

ALLERGY MANAGEMENT BEHAVIOURS AND
SOURCES OF STRESS FOR SCHOOLS AND FAMILIES
LIVING WITH LIFE-THREATENING FOOD ALLERGIES

CENTRE FOR NEWFOUNDLAND STUDIES

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Allergy Management Behaviours and
Sources of Stress for
Schools and Families Living with
Life-threatening Food Allergies

by

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A thesis submitted to the
School of Graduate Studies
in partial fulfilment of the
requirements for the degree of

Master of Science

Faculty of Medicine

Memorial University of Newfoundland

December 2005



St. John's

Newfoundland and Labrador

ABSTRACT

The purpose of this study was to describe the approaches taken by individuals, families, and school staff to the management of life-threatening food allergies, and to describe the sources of stress associated with managing this condition.

This was a cross-sectional descriptive study employing both quantitative and qualitative research methods using two instruments developed for the study. The principals from 40 randomly selected provincial schools were interviewed, as were 25 parents of children with food allergies attending schools in the province; 21 of the parents and 4 teens each also participated in one of four focus groups.

The results suggested that the reported number of students with food allergies in provincial schools has increased. While most schools demonstrated a positive approach to managing students with food allergies, one-quarter of the schools studied had many deficiencies in allergy management that may contribute to negative outcomes for families living with this stressful condition. Balancing individual rights, feelings of uncertainty, and increased workload were sources of stress for principals.

Many parents of children with life-threatening food allergies reportedly felt inadequately prepared by health professionals to safely manage their child's food allergy. Parents also identified inconsistent allergy management amongst schools in this province. The sources of stress for families included a perceived lack of control over allergies, inadequate public understanding and support, and the lack of reprieve from daily worries.

The results of this study support the need for a comprehensive provincial school policy on food allergy management, improved education by health professionals for school staff and families living with food allergies, and a public education and awareness campaign to increase understanding about the challenges of living with food allergies.

ACKNOWLEDGEMENTS

There are several persons whom I wish to acknowledge for their valuable contributions to the preparation of this thesis.

I wish to thank Dr. Sharon Buehler, my Principal Advisor, for offering her expertise in epidemiology, and for her informed opinion on quantitative research methodologies that is largely responsible for the standard of excellence achieved in this thesis.

I wish to express my appreciation to Dr. Shirley Solberg for her valuable input, particularly as it relates to qualitative research methodologies, and for her guidance in helping me to formulate and clarify the thoughts expressed in this thesis.

I thank Dr. Azza Hamed for providing her medical expertise and experience in the area of allergy and immunology in the critiquing of this research project.

I would like to extend my appreciation to the school principals, parents, and teens who generously agreed to participate in the study, the individuals who pilot tested the study instruments, and the school boards who facilitated the conduct of this research.

Special appreciation is extended to my parents for their unqualified support including providing grammatical editing of the thesis and transcribing the focus group discussions, but mostly for always being there when needed.

My deepest gratitude is extended to my husband, David, for his unconditional support and encouragement in every way possible, but especially for being an exemplary parent which allowed me the time to complete this thesis knowing that our children were in the best of care.

Most importantly, I wish to express my deep appreciation to each of my three children, Kathryn, Andrew, and Laura:

To Kathryn, for being a constant reminder of the most important role in my life, that of being a mother; and for demonstrating maturity beyond her years and numerous acts of affection that sustained me while writing this thesis;

To Andrew, for the countless ways that he helped to keep the home and the family in order, and for his selfless acts of kindness and consideration that were very much appreciated during this challenging time; and

To Laura, for her calm, mature approach to life's obstacles and for teaching me more than anybody how to live a happy, fulfilling life with a food allergy. She is the impetus for this thesis, and she is an inspiration to me always.

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CHAPTER I

Introduction

A food allergy is an adverse reaction that occurs in susceptible individuals following ingestion of a food or food additive. The most severe manifestation of food allergy is food-induced anaphylaxis, a potentially life-threatening, generalized allergic reaction to a food allergen such as peanuts, nuts or shellfish. The presentation and severity of each anaphylactic reaction is variable both within and between individuals, and hence is difficult to measure and predict (Sampson, 2003). This study addresses the daily management of life-threatening food allergies as described by individuals, families, and schools, and the sources of stress associated with this condition.

Food-induced anaphylaxis is considered a medical emergency with an onset of symptoms within minutes to hours of the ingestion of food (Sampson, 2000). A typical anaphylactic reaction often begins with a sensation of tingling of the lips and swelling of the throat and mouth. This can progress rapidly to difficulty swallowing, speaking, or breathing. Nausea, vomiting, and diarrhea often accompany anaphylaxis and individuals may report a sense of impending doom. Hives may be present on the skin, but may also be absent even in severe reactions. The individual may experience changes in heart rate and faintness associated with a drop in blood pressure. If not treated, anaphylaxis may progress to shock followed by collapse, unconsciousness and, potentially, death. The uncertainty and unpredictability of anaphylaxis, combined with the potential of a fatal outcome, explains the high levels of stress experienced by those who live with this condition. For many, this is a life long affliction as there are no known cures for food

allergies, and strict avoidance of the food allergen is the only way to prevent an anaphylactic reaction.

Most episodes of anaphylaxis occur unexpectedly in the community, not in a hospital setting (Simons, 2004). For this reason, individuals and their families must be prepared to initiate emergency treatment and transport the affected person to the nearest medical facility. The cornerstone of the emergency treatment of an anaphylactic reaction to food is an immediate injection of epinephrine. Delays in administering the epinephrine are associated with an increased risk of fatality (Sampson, 2003; Simons).

The prevalence of food-induced anaphylaxis in the population is unknown. A review of recent epidemiological studies suggest that up to 4% of the general population may suffer from food allergies (Sampson, 2004); food-induced anaphylaxis occurs in a portion of this percentage.

Rationale for the Study

Although the number of people in the general population with food allergies and food-induced anaphylaxis may be relatively small, their health and well-being are of concern to researchers and health professionals. Firstly, while there are no precise estimates of the prevalence of food-induced anaphylaxis, it has likely been under-recognized and under-reported in the past (Sampson et al., 2005). Even if only 4% of the general population, including children, suffer from food allergies, this prevalence rate translates to over one million Canadians affected by this condition. Results from the Canadian Paediatric Society Surveillance Program suggest that anaphylaxis may not be as rare in childhood as was once believed (Canadian Paediatric Society & Health Canada, 2001).

A second important consideration is that individuals with life-threatening food allergies are often otherwise healthy. If individuals with allergies are never exposed to the trigger, they may go on to live long, productive lives. The only way to prevent an allergic reaction is to avoid exposure to the offending food (Sampson, 1999b), but research has demonstrated that efforts at avoidance are not always successful (Sampson, 2000). The potentially fatal consequences of anaphylaxis in otherwise healthy individuals explains why this condition warrants further exploration.

Finally, consideration must be given to the psychological and social consequences for individuals living with life-threatening food allergies, and their families. There is a paucity of research on this subject, and the stress associated with this condition is likely under-recognized. Food allergies permeate all aspects of living including attendance at school and work, extracurricular activities, and traveling, to name a few (Gowland, 2001). When parents of children with food allergies have to relinquish their control over their children's well-being and place them in an environment, such as a school, that may be ill-prepared to manage food allergies, the result is increased stress for all involved (Primeau et al., 2000). To date, the sources of stress for individuals, families and schools who are managing children with food allergies are not well documented.

How individuals respond to stress may affect their allergy management behaviours. Little is known about the daily allergy management behaviours of children and families living with life-threatening food allergies. Evidence gathered from the study of fatal and near-fatal anaphylaxis suggests that the risk of fatality is influenced by both individual behaviours and situational circumstances at the time of an anaphylactic reaction (Sampson, Mendelson, & Rosen, 1992; Yunginger, Squillace, Jones, & Helm,

1989). In order to assess the behaviours that may place a child at increased risk of experiencing an anaphylactic reaction, one needs to first understand the day-to-day management behaviours of children and families living with life-threatening food allergies, an area that has limited research evidence to date.

Studies have also shown that food-induced anaphylaxis frequently occurs away from home and often at schools (Nowak-Wegrzyn, Conover-Walker, & Wood, 2001; Sicherer, Furlong, DeSimone, & Sampson, 2001). Schools may not, however, be prepared to prevent and treat anaphylactic emergencies (Boros, Kay, & Gold, 2000; Rhim & McMorris, 2001). The allergy management behaviours of school staff may have an impact on the child's risk of anaphylaxis while attending school, and on the final outcomes from such allergic reactions. Across Canada there are inconsistencies in the current management of students with life-threatening food allergies in schools (Anaphylaxis Canada, 2005). To begin the process of improving the school environment for students with food allergies, it is necessary to understand how schools currently manage students with life threatening food allergies, and the stress associated with this responsibility.

Study Purpose

The purpose of this study was to describe the approaches taken by individuals, families, and school staff to manage life-threatening food allergies, and the sources of stress associated with managing this condition. The specific objectives of this study were as follows:

1. To describe the number and characteristics of children and teens with life-threatening food allergies attending schools in Newfoundland and Labrador.

2. To describe the allergy management behaviours of school principals (or designates) who have students with life-threatening food allergies.
3. To describe the sources of stress for schools managing students with life-threatening food allergies, as identified by principals (or designates).
4. To describe the allergy management behaviours of children, teens, and families living with life-threatening food allergies.
5. To describe the sources of stress for families living with children who have life-threatening food allergies, as identified by parents and teens.

Definitions for the Study

Life-threatening Food Allergy

A food allergy that has been diagnosed by a physician for which epinephrine has been prescribed, to be administered in the event of an anaphylactic reaction.

Allergy Management Behaviour

Any behaviour on behalf of children, parents, or school staff aimed at preventing and treating allergic reactions in individuals with life-threatening food allergies.

Sources of Stress

Anything that causes increased stress for children, parents, and schools coping with the management of life-threatening food allergies.

Principal's Designate

The member of the school staff who has been designated by the principal as responsible for the management of students with life-threatening food allergies.

CHAPTER II

Review of the Literature

It has been more than a century since Portier and Richet made a seminal contribution to the understanding of hypersensitivity mechanisms and the manifestations of *anaphylaxis*, a word derived from the Greek words *a* meaning “against”, and *phylaxis* meaning “protection” (Cohen & Zelaya-Quesada, 2002). Since the discovery of allergy and anaphylaxis, much research has been reported to explain a condition that affects a growing number of individuals. The following review of the literature will begin with definitions of food allergies and anaphylaxis, and provide the background information necessary to understand the complexities of these conditions. This will be followed with a report of the available research on the prevalence of food allergy and anaphylaxis, both worldwide and within Canada. The situational circumstances and individual behaviours that may contribute to grave patient outcomes from anaphylaxis will be examined through a review of retrospective studies and case reviews of fatal and near-fatal anaphylaxis. Finally, the empirical evidence on the psychological impact of living with food allergies, and the management of these allergies in the school environment will be reviewed.

Definitions and Background Information

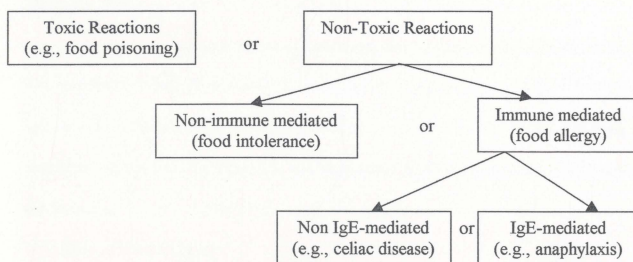
Definitions of Adverse Food Reactions and Food Allergies

A variety of adverse food reactions has been reported by individuals following ingestion of a food or food additive. Not all are true allergic reactions. In response to the lack of standardized definitions of adverse food reactions, the European Academy of Allergy and Clinical Immunology (EAACI) prepared a position paper on adverse

reactions to foods (Brujinzeel-Koomen et al., 1995). A new classification system based on the mechanisms of adverse food reactions (i.e., immune versus non-immune mechanisms) was proposed to replace an earlier system prepared in 1984 by the American Academy of Allergy and Clinical Immunology (AAACI) and the National Institutes of Health (NIH). The new system is supported by scientific evidence and is well accepted in the field of allergy research (Sampson, 2004).

Adverse food reactions may be classified as either toxic reactions or nontoxic reactions (see Figure 1). A *toxic reaction* to food can occur in anybody provided there is a sufficient dose ingested. *Non-toxic reactions* depend on individual susceptibility and may be the result of either immune or non-immune mechanisms.

Figure 1. Classification of adverse reactions to food.



Food intolerance is an adverse physiological response to a food or food additive that is non-immunological in nature. This may include pharmacological reactions to a chemical in the food (e.g., caffeine), metabolic disorders such as enzyme deficiencies (e.g., lactase deficiency resulting in lactose intolerance), or undefined food intolerance

(Bruijnzeel-Koomen et al., 1995; Sampson, 1999a; Yeung, Applebaum, & Hildwine, 2000).

Food allergy can be subdivided into immunoglobulin E (IgE)-mediated or non-IgE-mediated reactions (e.g., celiac disease). IgE-mediated food allergies exist only in those people who react to a *food allergen*, a protein found in food that stimulates the immune system to produce IgE antibodies. This process sensitizes the individual. Subsequent exposures to the same allergen stimulate mast cells and basophils to release mediators that result in the signs and symptoms of allergy (Bruijnzeel-Koomen et al., 1995; Yeung et al., 2000). The factors leading to the propensity of the body to produce IgE antibodies against common substances like foods are not well understood. However, two of these factors include a genetic predisposition and an exposure to allergens (Sampson, 2002).

Food-induced allergic reactions may result in a variety of symptoms involving the skin, respiratory tract, gastrointestinal tract, and/or cardiovascular systems. Symptoms may develop within seconds to hours after ingestion of a food allergen. Anaphylaxis represents the most severe form of a food-induced allergic reaction, and is the focus of this research.

Definition of Anaphylaxis

To date, there is no universally accepted definition of anaphylaxis (Clark et al., 2004; Fogg & Pawlowski, 2003; Sampson et al., 2005). This has led to inconsistencies and disagreements about the prevalence, diagnosis, and management of anaphylaxis. In April 2004, the National Institute of Allergy and Infectious Diseases (NIAID) and the Food Allergy and Anaphylaxis Network (FAAN) in the United States brought together

experts from various disciplines and 12 other professional, governmental and lay organizations at a symposium on the definition and management of anaphylaxis (Sampson et al.). This symposium served as a starting point for the future development of a clinical definition of anaphylaxis, a strategy to manage anaphylaxis, and an agenda for future research on anaphylaxis.

While there is a lack of consensus about the definition of anaphylaxis, it is generally agreed that anaphylaxis is a severe and potentially life-threatening form of an allergic reaction precipitated by a variety of agents including foods, medications, vaccines, latex, and insect venoms (Ellis & Day, 2003; Kemp & Lockey, 2002; Sampson et al., 2005; Yeung et al., 2000). In the absence of a universally accepted definition of anaphylaxis, the Canadian Paediatric Surveillance Program defined *anaphylaxis* as “a severe allergic reaction to any stimulus, having sudden onset and generally lasting less than 24 hours, involving one or more body systems and producing one or more symptoms such as hives, flushing, itching, angioedema, stridor, wheezing, shortness of breath, vomiting, diarrhea, or shock” (Simons, Chad, & Gold, 2002, p.181). Anaphylaxis may be viewed as a syndrome involving one or more organ systems either alone or in combination. The cluster of clinical symptoms exhibited by individuals experiencing anaphylaxis varies, both within individuals (experiencing multiple reactions) and between individuals (Sampson, 2003). A comprehensive list of the clinical signs and symptoms of anaphylaxis are summarized in Appendix A.

There is no consensus for determining the level of severity of an allergic reaction, and for deciding at what point an allergic reaction should be classified as anaphylaxis (Sampson et al., 2005). Some researchers have proposed a gradation system that might be

used both clinically and in the conduct of research to indicate the severity of an anaphylactic reaction (i.e., graded as a mild, moderate or severe reaction) (Sorensen, Nielsen, & Ostergaard Nielsen, 1989), but this system is not universally accepted (Sampson et al., 2005).

Idiopathic anaphylaxis refers to anaphylaxis of unknown cause or origin (Weiler, 1999). This is a particularly worrisome condition for both physician and patient as it is difficult to know how to avoid the allergen when the allergen cannot be identified.

Food-induced anaphylaxis is the most common cause of anaphylaxis treated in emergency departments in the United States (Sampson et al., 2005). Reactions may be described as uniphasic reactions, which resolve within hours of treatment, or biphasic reactions which affect approximately 20 to 30 % of patients (Ellis & Day, 2003; Lee & Greenes, 2000). Patients experiencing biphasic reactions initially develop the usual symptoms of anaphylaxis and then appear to recover. A quiescent period of one to three hours (or longer) may ensue, followed by a recurrence of sudden, severe symptoms. Biphasic and protracted symptoms are potentially dangerous to the patient who may believe he/she has fully recovered and thus delay treatment (Sampson, 2000).

Food-associated, exercise-induced anaphylaxis is being reported more frequently in the literature. Individuals afflicted with this disorder can usually ingest a food (e.g., wheat or shellfish) without experiencing an allergic reaction. If the individual combines ingestion of the same food allergen with exercising within 2 to 4 hours of eating, however, symptoms of anaphylaxis develop (Sampson, 2000).

Theoretically, any food protein is capable of causing an anaphylactic reaction. The most common foods associated with anaphylaxis include peanuts, tree nuts (e.g.,

walnuts, almonds), fish (e.g., cod, salmon), shellfish (e.g., shrimp, scallop), milk, eggs, seeds (e.g., sesame seed), and fruit (e.g., kiwi). Unfortunately, reactions to peanuts, tree nuts, fish, and shellfish tend to result in allergies that are life-long (Sampson, 2000, 2003). The risk of an allergic reaction to a food depends on several factors including the potential of a particular food allergen to elicit a reaction, the manufacturing process (e.g., cross-contamination in food industry), the amount of food ingested by the individual, and the sensitivity of the individual to the offending food (Bjorksten, 2004).

Diagnosis of Food Allergy and Food-induced Anaphylaxis

The diagnosis of a food allergy involves several stages beginning with a thorough medical history and physical examination by a physician (Sampson, 1999b, 2000). A food allergy is diagnosed based on clinical signs and symptoms (see Appendix A), and the temporal relationship between the ingestion of a suspected food and the onset of symptoms. Consideration must be given to hidden ingredients in foods, and to the possibility that a food may be cross-contaminated with protein from another food (e.g., through shared cooking utensils or during food preparation). Laboratory tests are useful in establishing the presence of allergen-specific IgE in a person suspected of having a food allergy, however, the results of these tests must be considered in combination with the history of symptoms experienced by the individual following the ingestion of the suspected food (Sampson, 1999b, 2000).

Once a food has been identified as the possible source of an allergic reaction, a diagnostic allergen elimination diet may be followed to provide support for the diagnosis. The *gold standard* for the diagnosis of a food allergy is the double-blind placebo-controlled food challenge (DBPCFC) whereby neither the patient nor the physician

knows the food content of the challenge. For individuals with histories of life-threatening anaphylaxis, these challenges should be executed with caution and only in an environment where there are trained personnel and equipment to handle anaphylaxis (Sampson, 1999b).

The absence of a universally accepted definition of anaphylaxis has impeded the definitive diagnosis of food-induced anaphylaxis (Fogg & Pawlowski, 2003; Sampson et al., 2005). The distinction between food allergy and food-induced anaphylaxis is, at times, unclear and is related to the overall severity of the reaction (Sampson et al., 2005).

Natural History of Food Allergy

The natural history of food allergy refers to the natural development of sensitivity to a specific food, and the possible loss of such sensitivity over time (Bock, 1982). Bock (1987) conducted one of the first prospective studies of the natural history of food allergy in 480 children who were followed from birth to their third birthday. Out of the 480 children, 28 % were *thought* by their parents to have food-related symptoms, but only 8 % had reactions confirmed by an oral food challenge. The majority of the initial complaints (80 %) occurred in the first year of life, but by age three, most foods could be reintroduced into the diet without risk.

Bock and Atkins (1989) went on to conduct a longitudinal study on the persistence of peanut allergy years after diagnosis and concluded that none of the 32 patients followed over a 2 to 14 year period had demonstrated that they had outgrown their peanut allergy. A review of several subsequent studies on the natural history of food allergy suggests that the prevalence of food allergy is greatest, at 6 to 8 %, in the first year of life but falls to about 2 % by age 10 years (Sampson, 1996; Wood, 2003).

Children often outgrow their hypersensitivity to milk and egg in early childhood. Those with allergies to peanuts, tree nuts, fish, or shellfish, however, rarely lose their reactivity and must adjust to a lifelong food allergy. Strict avoidance of the food allergen is believed to increase an individual's chances of outgrowing an allergy, though there is little empirical evidence to support this (Wood). Fogg and Pawlowski (2003) reviewed studies published after the year 2000, and they asserted that up to 20 % of children with peanut allergy *may* have outgrown their sensitivity, though a small number of these children were found to be re-sensitized at a later date, especially those who did not continue to ingest peanuts on a regular basis.

Primary Prevention of Food Allergy

The primary prevention of food allergies is a controversial area and is likely possible only in infancy and early childhood (Bruijnzeel-Koomen et al., 1995). Breast-feeding for as long as possible may delay rather than prevent the development of food allergies. Other preventive measures that have been investigated include eliminating allergenic foods from the mother's diet during pregnancy and lactation, particularly if the mother has a family history of allergy, using specially formulated milk supplementation, and delaying, for at least the first two to three years, the introduction of common food allergens (e.g., peanuts, eggs, and fish) into the diet of infants and children who are at high risk for food allergy. To date, there is insufficient evidence to make conclusive recommendations regarding prophylactic measures to prevent food allergies (Fogg & Pawlowski, 2003; Sampson, 1996, 2002).

Recommendations on the Management of Anaphylaxis

While there is ongoing research into several promising therapies for preventing food allergies and desensitizing individuals with existing allergies, to date none of the therapies have proven to be truly effective (Fogg & Pawlowski, 2003; Sampson, 2003).

Long-term Management of Food Allergy

The cornerstone of the long-term management of life-threatening food allergies is the prevention of accidental exposure to the food allergen. This involves the education of the patient, family, and the school community about label reading, hidden ingredients in foods, cross-contamination of "safe" foods through contact with allergenic foods, the symptoms of anaphylaxis, and the appropriate emergency response (Munoz-Furlong, 2003; Sampson, 2000). Individuals with food allergies are often advised to avoid high-risk situations such as eating at buffets, receptions, restaurants (Furlong, DeSimone, & Sicherer, 2001), and school cafeterias (Sampson, 1999b, 2002). The food industry has responded to the strict avoidance needs of allergic individuals by placing precautionary labels, otherwise known as "may contain" disclaimers, on foods processed in the same facility as allergenic foods, where the likelihood of cross-contamination exists (Taylor et al., 2002). This effort to protect the manufacturer and the well being of the allergic consumer, however, places further restrictions on food choices (Munoz-Furlong).

Acute Management of Anaphylaxis

Despite efforts on behalf of individuals with food allergies to avoid the foods to which they are allergic, accidental ingestion poses an inevitable risk, thus precipitating life-threatening acute anaphylactic reactions that require an immediate emergency response. A cornerstone of the acute management of an anaphylactic reaction to food

occurring in an individual in the community is an immediate injection of epinephrine administered into the thigh muscle followed by transport to the nearest medical facility. Epinephrine (adrenaline) works to maintain an open airway for breathing and support the circulatory system. Individuals who are at high risk for food-induced anaphylaxis should be prescribed epinephrine for self-administration, especially those who have asthma or who have had a previous allergic reaction involving the airway or cardiovascular system (Sampson, 2000, 2003; Simons, 2004). Other medications, such as antihistamines and bronchodilators, may be added to the treatment of acute anaphylaxis but should not replace the first-line treatment of an injection of epinephrine (Sampson, 2000, 2003; Simons; Simons, Gu, & Simons, 2001). Studies suggest that delays in administering epinephrine are associated with an increased incidence of biphasic reactions (Fogg & Pawlowski, 2003; Lee & Greenes, 2000) and can contribute to fatal outcomes (Sampson; Simons). Even when epinephrine is used promptly, it is not always effective in severe anaphylaxis (Golden, Schwartz, Graft, & Bock, 1994; Sampson, 2002).

Self-administered epinephrine is usually prescribed in the form of an EpiPen® (Allerex Laboratories, Kanata, Ontario, Canada), an auto-injector that consists of a spring-activated needle that is hidden until activated by the user with enough epinephrine for a single intramuscular injection (Sampson, 2003). Individuals experiencing severe anaphylactic reactions may require the administration of more than one EpiPen®, at 15 to 20 minute intervals, until the individual can reach the nearest hospital or medical facility for further treatment (Sampson, 2003).

The cost of purchasing an EpiPen® is \$90 to \$100 and there is considerable variability among insurance policies regarding coverage. Families receiving provincial

government assistance are often allotted only one EpiPen® (unless special authorization is given for additional EpiPens®). This is impractical for children and families who live more than 20 to 30 minutes from the nearest medical facility. The expiry date for the medication in the EpiPen® is generally 1.5 to 2 years after purchase, which further adds to the expense of living with a life-long allergy.

Effective emergency management of an anaphylactic reaction presumes that the individual responding knows when and how to properly administer the EpiPen®. Several empirical studies, however, indicate that many patients who are prescribed an EpiPen® cannot properly use them. Four recent studies of adults and parents of children with food allergies revealed two knowledge deficiencies: (a) They did not know how to recognize the symptoms of anaphylaxis and hence were uncertain about when they should administer the EpiPen® (Blyth & Sundrum, 2002; Gold & Sainsbury, 2000), and (b) when asked to demonstrate the steps in the proper administration of an EpiPen® using a trainer device, many of the patients and parents made errors that could have resulted in grave consequences in the event of an anaphylactic reaction (Huang, 1998; Blyth & Sundrum; Gold & Sainsbury; Sicherer, Forman, & Noone, 2000). Parents of children who had experienced a number of allergic reactions in the past seemed to have greater knowledge about symptoms and proper EpiPen® usage (Gold & Sainsbury).

In one study, the parents reported that the physician who prescribed the EpiPen® had provided both verbal and written instructions on the use of the auto-injector device (Gold & Sainsbury, 2000) but, in general, patients reported that the prescribing physician did not actually demonstrate how to use it (Huang, 1998). The results of these studies support the notion that while EpiPens® may be prescribed by physicians for the acute

management of anaphylaxis, they are not widely used as intended in the community (Simons, 2004). In terms of patient outcomes, EpiPen® use during an anaphylactic reaction was associated with a reduction in both the subsequent use of epinephrine in hospital and in-hospital admissions.

In an attempt to address the problem of knowledge deficiencies amongst individuals and families living with life-threatening food allergies, Gold and Sainsbury (2000) also questioned 29 attending paediatricians and found that only 21 % were familiar with and able to correctly demonstrate the use of an EpiPen® device. Similarly, Grouhi, Alshehri, Hummel, and Roifman (1999) examined the knowledge levels of 122 health professionals, including emergency physicians, family doctors, and paediatricians, and found that only one-quarter could correctly demonstrate the steps in administering an EpiPen®. When asked, the majority of these physicians did not have an EpiPen® trainer device in their office to be used in patient teaching. The investigators concluded that both patients and physicians need improved education and repeated review of the technique to ensure the proper use of this life-saving device. The results of one prospective study of the impact of education on parental knowledge, the management of allergic reactions, and EpiPen® use, supported the notion that parents who received a comprehensive education program which included a paediatric allergy specialist, a clinical nurse specialist, and a dietician, showed statistically significant improvement in their knowledge levels three months later and a reduction in the rate of allergic reactions one year later (Kapoor et al., 2004).

In summarizing the available evidence on the management of anaphylaxis, several claims can be made: (a) Individuals with life-threatening food allergies must exercise

extreme vigilance in an effort to avoid the accidental ingestion of allergenic foods; (b) accidental ingestion of food allergens can be life-threatening and result in a medical emergency; (c) the treatment of choice for food-induced anaphylaxis is self-injectable intramuscular epinephrine; (d) epinephrine must be carried at all times, is costly, expires after a period of time and must be replaced; and (e) both patients and physicians require further education and support in order to ensure the correct and timely use of these life-saving devices.

Prevalence of Food Allergy and Food-induced Anaphylaxis

The following is a review of the empirical literature on the prevalence of food allergy in general, and of food-induced anaphylaxis specifically.

Prevalence of Food Allergy

There is a tendency amongst the general public to overestimate the prevalence of food allergy due, in part, to confusion over what constitutes a true food allergy (Altman & Chiaramonte, 1996; Boros et al., 2000; Bjorksten, 2004; Jansen et al., 1994; Sloan & Powers, 1986; Young, Stoneham, Petrukevitch, Barton, & Rona, 1994).

A prospective cohort study of 1218 children born in the Isle of Wight from 1989 to 1990 revealed that, based on positive skin prick tests, 1.2 % of children were sensitized to peanut or tree nut by age four years (Tariq et al., 1996). Taking into consideration the epidemiological data available in the mid-1990s, Sampson (1996) concluded that the prevalence of food allergy in the general population was approximately 1 to 2 %, and appeared to be increasing. This number may have been closer to 8 % amongst children less than three years of age (Bock, 1987).

Towards the year 2000, Sicherer and others conducted two nation-wide, cross-sectional, random digit dial telephone surveys of households in the United States to describe and compare the self-reported prevalence rates for peanut and tree nut allergy (Sicherer, Munoz-Furlong, Burks, & Sampson, 1999; Sicherer, Munoz-Furlong, & Sampson, 2003). The results of the two surveys, held 5 years apart, suggested a possible trend towards increasing prevalence rates of allergy to peanut and tree nut amongst children younger than 18 years of age, a trend that was further supported by the results of a second cohort study in the Isle of Wight (Grundy, Matthews, Bateman, Dean, & Arshad, 2002). The second cohort study included 2878 children born between 1994 and 1996 who were subjected to skin prick tests for peanut followed by oral food challenge to confirm the allergy. When these results were compared with the cohort born in 1989, there was a three-fold increase in the number of children who were sensitized to peanut.

Two recent epidemiological surveys, one in France and the other in the United States, provided further support for the notion that the prevalence of food allergies is higher than previously reported (Kanny et al., 2001; Sicherer, Munoz-Furlong, & Sampson, 2004). Sampson (2004), in his most recent review of the epidemiological evidence on food allergy concluded that the prevalence rate for food allergies in the general population could even be as high as 3.5 to 4 %, affecting millions of Americans. Individuals with histories of asthma, eczema, and allergic rhinitis have a higher prevalence of food allergy (Sampson, 2004).

The exact prevalence of food allergies in Canada is difficult to determine. One recent study in Montreal, Quebec, was the first in North America to corroborate a reported history of peanut allergy with diagnostic testing to confirm the allergy (Kagan et

al., 2003). A random sample of 7768 students in Kindergarten to Grade 3 in public and private schools were included in the sample and over 4000 children responded. The investigators concluded that the prevalence of peanut allergy in this age group exceeded 1.0 % and may have been as high as 1.5 %, results that mirrored those of the cohort study in the Isle of Wight, United Kingdom.

From a local provincial perspective, the 1998/99 National Population Health Survey (NPHS) estimated that 4.6 % of the population of Newfoundland and Labrador reportedly had a *food allergy diagnosed by a physician*, which had increased from 3.4 % in 1994/95 (NPHS, 1994/95, 1998/99). The data did not distinguish between the severities of the allergic disease and did not identify anaphylaxis specifically. There are no population survey data available for children up to 11 years of age, but a recent Canadian Community Health Survey reported that, for individuals 12 years of age and older in Newfoundland and Labrador, 4.3 % in 2000/2001 and 5.1 % in 2003 had been *diagnosed by a health professional with a food allergy* (CCHS, Statistics Canada, 2000/2001, 2003). These numbers were slightly lower than the national estimates of approximately 7 % in both surveys, but provide evidence to suggest an increasing number of Canadians with food allergies.

Another, less rigorous approach to examining the prevalence of food allergies in school-aged children in this province was undertaken when the Coalition for School Nutrition (2001) conducted a survey of all schools in Newfoundland and Labrador, in part to estimate the number of schools in the province that had a student with a food allergy. Based on a 72 % response rate and a mean enrolment of 269 students per school, the survey results reported 1.3 students per school with food allergies *severe enough to*

require an EpiPen®. These numbers were slightly higher in the St. John's region (2.8 students per school), the region that also had the highest average student enrolment (mean enrolment of 432 students per school). A similar survey of school children in a random sample of 100 state schools in the Severn NHS Trust, England, reported that over half of the 83 schools that responded had at least one student with an allergy to peanut or tree nut (Watura, 2002). Another study of 109 public elementary school principals in the United States found that 87 % of schools had at least one student with a food allergy (Rhim & McMorris, 2001). In all school surveys, the number of students with food allergies may have been under-estimated as there were likely students with food allergies who were not known by the principal.

Prevalence of Food-induced Anaphylaxis

There is no universally accepted definition of anaphylaxis and this has resulted in difficulties in estimating the true prevalence rates for this condition (Wuthrich & Ballmer-Weber, 2001). The annual reported rates for anaphylaxis in response to a *variety* of potential allergens (e.g., foods, latex, medications, bee stings, etc.) has varied in several studies conducted world wide due, in part, to the fact that each study used different inclusion criteria for defining a case of anaphylaxis (Mullins, 2003; Sorenson et al., 1989; Yocum et al., 1999).

The true prevalence rates for *food-induced* anaphylaxis have likely been underestimated (Sorensen et al., 1989; Yocum et al., 1999). Part of the problem in identifying cases of food-induced anaphylaxis lay in the fact that, until 2001, the International Classification of Diseases (ICD) lacked specific codes for the diagnosis of food allergy or food-induced anaphylaxis (Sampson et al., 1992; Yocum & Khan, 1994).

Until then, under ICD Version 9, food allergy was included under the code for dermatitis (693.1 or 692.5). Further, the code for anaphylactic shock (995) included, but was not specific to, food allergies. Hence, many cases went unidentified, unreported, or erroneously reported. The ICD Version 10, implemented in April 2001, included for the first time a unique code for *anaphylactic shock due to adverse food reaction* (T78.0). A report from a symposium on the definition and management of anaphylaxis stated, however, that these codes remain underused (Sampson et al., 2005).

In 2003, Sampson (2003), drawing upon the results of earlier surveys, predicted approximately 30,000 episodes of food-induced anaphylaxis in the US each year accompanied by 2000 hospitalizations and 150 to 200 deaths. He concluded that food-induced anaphylaxis may account for one-third to one-half of all anaphylactic reactions treated in emergency departments in hospitals in North America, Europe, and Australia. Hence, anaphylaxis is a medical condition with potentially grave consequences that affects a significant portion of the population.

There are no epidemiological studies of the prevalence of life-threatening food allergies in Canada. In 1996, the Canadian Paediatric Surveillance Program was established to provide ongoing surveillance of the occurrence of rare childhood disorders, such as anaphylaxis, through voluntary monthly reports provided by paediatricians, sub-specialists, and other health care providers (Canadian Paediatric Society & Health Canada, 2001). The anaphylaxis surveillance program was initiated in recognition of the fact that anaphylaxis is a severe, potentially fatal allergic reaction that is under-diagnosed and under-treated in children.

Each month during the eighteen-month surveillance period from 2000 to 2001, 130 physicians voluntarily reported on 747 cases of anaphylaxis from all causes. Amongst the anaphylactic reactions reported 60 % occurred in males, and 60 % occurred in preschoolers. The majority of the reactions (81 %) were stimulated by foods, especially peanuts, tree nuts, cow's milk, eggs, fish/shellfish, and fruits/vegetables. The report concluded that anaphylaxis is not as rare in childhood as once believed, and that the occurrence rate for anaphylaxis was likely underestimated by this study. For example, some milder episodes of anaphylaxis may not have been recognized as such by the child's caretaker or physician. Cases that were treated by the family physician and were not referred to a specialist would have been missed by this survey. Adolescents, in particular, may have been less likely to visit a paediatrician, and this would account for an under-representation of this age group in the surveillance program.

In Newfoundland and Labrador, data collected from all acute care facilities in the province on hospital separations with a diagnosis of *anaphylactic shock due to adverse food reaction* (ICD code T78.0), indicated that in the 1 to 25 year age group, there were five cases of anaphylaxis in the two year period from 2001 to 2003 (NLCHI, 2002, 2003). Data on frequency of visits to the Emergency Department for the treatment of food-induced anaphylaxis are not systematically tracked in the acute care facilities of this province, which further contributes to the inability to obtain a true measure of the prevalence of this life-threatening condition in the province.

Common Factors Associated with Food-induced Anaphylaxis

Retrospective reviews of medical records, studies of recurrent anaphylaxis, and case series reviews of fatal and near-fatal anaphylaxis elucidated many common factors

associated with anaphylaxis. These included individual factors, such as personal health histories and individual allergy management behaviours, and situational factors and circumstances that contributed to the occurrence of anaphylaxis.

Retrospective Studies of Anaphylaxis

An analysis of the results of four retrospective reviews of medical records revealed several factors that were common in all documented cases of anaphylaxis (Clark et al., 2004; Dibs & Baker, 1997; Kemp, Lockey, Wolf, & Lieberman, 1995; Yocum & Khan, 1994). Three of the studies, published in the 1990s, were based upon chart reviews from two adult clinics and one children's hospital; the fourth study, published in 2004, came from a multicenter review of emergency department visits for food allergies. All studies were conducted in the United States.

Amongst adult patients, more females than males experienced anaphylaxis, with a case ratio of approximately 60 % females and 40 % males (Clark et al., 2004; Kemp et al., 1995; Yocum & Khan, 1994). Children with anaphylaxis showed a reversal of this trend with 56 % males and 44 % females in the chart review (Dibs & Baker, 1997). The majority of patients who experienced anaphylaxis had a history of other allergic conditions such as asthma, eczema and rhinitis. Approximately one-third of patients with anaphylaxis had had one or more prior non-anaphylactic reaction to the allergen, and many had also had prior anaphylactic reactions.

The causes of the anaphylaxis were reported based on reviewing the temporal relationship between exposure to the allergen and the onset of anaphylaxis, and through positive skin test results. Chart reviews revealed that the diagnosis was not confirmed using the gold standard of a DBPCFC in all cases. Despite this limitation, the foods that

reportedly accounted for most of the episodes of food-induced anaphylaxis in all four retrospective chart reviews included seafood, peanuts, and tree nuts. The remainder of the anaphylactic reactions were believed to have been caused by one of medications, insect stings, latex, or exercise. Several of the adult patients had idiopathic anaphylaxis of unknown origin (Kemp et al., 1995; Yocum & Khan, 1994).

Amongst children, the majority of reactions (12 out of 14 reactions) to foods occurred at home or in a relative's home, and none were fatal (Dibs & Baker, 1997). Eleven of these children had known histories of food allergies, which further suggested that, despite efforts to eliminate allergens from the diet, food allergens were sometimes unavoidable. Only 3 of the 14 children had self-injectable epinephrine available for use, and only two of the three administered it successfully at the time of the reaction. The results from these retrospective studies of the paediatric population concur with the statistics coming out of the Canadian Paediatric Survey (Canadian Paediatric Society & Health Canada, 2001). In Canada, two-thirds of the anaphylactic reactions occurred in the home and the parent was present during 75 % of the reactions. The children had a known history of food allergy, but epinephrine was administered in only one-third of the cases, either because it was unavailable or the individuals present did not give it to the child.

Studies of Recurrence of Anaphylaxis

Little is known about the characteristics of individuals who experience recurrent anaphylaxis. Three prospective studies that followed groups of patients with a known history of anaphylaxis provided empirical evidence for the risk factors for recurrence (Cianferoni et al., 2004; Kemp et al., 1995; Mullins, 2003). Mullins follow-up study of over 300 patients with anaphylaxis found that in any given one-year period, 1 in every 12

patients with a history of anaphylaxis experienced recurrence. Most relapses were associated with the accidental ingestion of peanut or tree nut. Another study of children found that one-third of the patients they followed experienced recurrent anaphylaxis (Cianferoni et al.), and the risk was higher if they were allergic to at least one food or had atopic dermatitis (eczema). As with the retrospective chart review, compliance with carrying and using epinephrine was poor. The likelihood that patients carried epinephrine was inversely proportional to the time since they were originally assessed for anaphylaxis (Mullins). In one study, almost half of the adults did not carry epinephrine for self-administration (Kemp et al.). Those with idiopathic anaphylaxis were more likely to carry epinephrine than those with identifiable causes. During informal questioning, subjects offered that they did not carry epinephrine because they “felt safe” since they had not had a reaction for a long time, or that they “simply forgot”.

Case Reviews of Fatal and Near-fatal Anaphylaxis

Since it is not ethically or practically possible to subject patients to randomized controlled trials of anaphylaxis, a review of cases of fatal and near-fatal anaphylaxis provides a valuable methodology for examining risk factors associated with grave patient outcomes. Five such studies provided information about the situational circumstances and individual behaviours associated with fatal and near-fatal food-induced anaphylaxis. A summary of the key features of these five studies is presented in Table 1 (Bock, Munoz-Furlong, & Sampson, 2001; Pumphrey, 2000; Salter, Mehral, Cairns, Sussman, & Vadas, 2001; Sampson et al., 1992; Yunginger et al., 1988).

With the exception of Pumphrey's (2000) review of all fatal reactions in the United Kingdom since 1992, almost equal numbers of males and females had

Table 1

Summary of Key Features of Case Reviews of Fatal and Near-fatal Anaphylaxis

Study	Sample	Other hyper-sensitivity disorders	Prior allergic reaction	Allergenic food	Location of reaction
Yunginger et al. (1988)	<u>Fatal</u> : n = 7 Males: 5 Females: 2 Age: 11 - 43	All Asthma Eczema Rhinitis	All	Peanuts (4) Nut (1) Shellfish (1) Fish (1)	Home (1) Outside home (6) (School: 1 of 6)
Sampson et al. (1992)	<u>Fatal</u> : n = 6 Males: 5 Females: 1 Age: 2 - 26 <u>Near-fatal</u> : n = 7 Males: 2 Females: 5 Age: 9 - 17	All Asthma Eczema Rhinitis	All	<u>Fatal</u> : Peanut (3) Nut (2) Egg (1) <u>Near-fatal</u> : Peanut (1) Nut (4) Milk (2)	<u>Fatal</u> : Home (1) Outside home (5) (School: 4 of 5) <u>Near-fatal</u> : Private homes (7)
Pumphrey (2000)	<u>Fatal</u> : n = 39 Males: 12 Females: 27 Age: 8 - 67	Some Asthma	All	Peanut (10) Nut (15) Seafood (3) Milk (2) Other (7) Unknown (2)	Home (6) School (2) Restaurant (22) Party (2) Other (5) Unknown (2)
Bock et al. (2001)	<u>Fatal</u> : n = 32 Males: 16 Females: 16 Age: 2 - 33	All but one Asthma	All but one	Peanut (20) Nut (10) Milk or fish (2)	Home (5) School (4) Restaurant (18) Other (5)
Salter et al. (2001)	<u>Fatal</u> : n = 32 (2 not reported) Males: 15 Females: 17 Age: 9 - 78	Most (68 %) Asthma	Most	Peanut and nut (20) Seafood (3) Milk (1) Other (3) Unknown (3)	Home (10) School or camp (6) Restaurants (12) Other (2)

experienced fatal or near-fatal anaphylaxis. All or most had asthma, other allergic conditions, and a history of previous allergic reactions. In the series of 32 fatal reactions reported by Bock et al. (2001), 54 % of the patients were in the 10 to 19 year age group, suggesting that teens may be at a higher risk for fatal anaphylaxis. The most common foods precipitating the reactions were peanuts, tree nuts, fish, and shellfish. While most anaphylactic reactions occurred in the home, those that resulted in fatality were more likely to occur outside the home such as in schools, daycares, or restaurants. The investigators emphasized that anaphylactic reactions may be more easily and successfully treated within a private home than in public places.

A synthesis of the result of this case review revealed a set of common factors that may have contributed to the occurrence of fatal or near-fatal anaphylactic reactions. These factors may be further sub-divided into situational circumstances and individual allergy management behaviours that contributed to grave patient outcomes. Some of the situational circumstances that may have contributed to fatal or near-fatal outcomes included: a) never receiving a prescription for epinephrine from the physician, b) inadequate labelling of the contents of packaged foods, c) a lack of awareness among restaurant personnel about the ingredients in foods and methods of preparation that could result in cross-contamination, d) a lack of awareness and education about allergy management in schools, e) a lack of available emergency medications and equipment on the ambulances responding to anaphylactic emergencies, f) the use of alternative less effective emergency medications by medical personnel, and g) being caught off-guard by a biphasic anaphylactic reaction.

The individual allergy management behaviours that may have contributed to fatal or near-fatal outcomes from an anaphylactic reaction included: a) failure to carry epinephrine at all times, or failure to administer it even when available; b) denial of the initial symptoms thus further delaying the administration of the epinephrine; c) use of oral antihistamines to treat the reaction; d) use of alcohol which clouded the patient's judgment in the face of a reaction; and e) failure to read package labels or inquire about food preparation in restaurants due, in part, to the development of a complacent attitude toward ingesting the offending food.

The low levels of compliance with carrying and using epinephrine to treat anaphylaxis are an important behavioural factor that contributed to many of the reported deaths (Pumphrey, 2000). Salter et al. (2001) reported that two patients died while running to get the epinephrine that was within a 100 to 200 foot radius. Sampson et al. (1992) reported that none of the six patients who had fatal outcomes carried epinephrine, despite the fact that it was prescribed for three of them. The presence of parents did not seem to make a significant difference between the fatal and near-fatal groups in this study, as some parents did not appreciate the potential severity of the allergic reactions. When comparing the two groups in this study, those who experienced near-fatal reactions developed symptoms very quickly after ingestion and most received epinephrine within 30 minutes. In comparison, the six patients who died from anaphylaxis had delayed symptoms and only two received epinephrine within the first hour of the onset of reaction. Pumphrey pointed out that anaphylactic reactions that begin primarily with respiratory symptoms may be mistakenly diagnosed as asthma, which may contribute to the delay in appropriate treatment.

Most, if not all, of the persons in the case series were known to have a food allergy and had had previous allergic reactions prior to the fatal reaction, which points to the difficulty in avoiding allergenic foods, and the need for improved package labelling and further education of individuals, families, school staff, restaurant personnel, physicians, and emergency response technicians. Furthermore, the decisions and behaviours of those living with life-threatening food allergies may have placed them at risk for episodes of anaphylaxis.

Sources of Stress Associated with Life-threatening Food Allergies

There is a paucity of empirical literature that addresses the impact of food allergies upon the psychological and social well-being of individuals and families. The impact of living with food allergies, and the associated sources of stress, can be viewed from at least three perspectives: a) parental perceptions of the impact on the child who has the food allergy, b) parental perceptions of the impact of the child's food allergy on the family, and c) perceptions held by children and adults who are living with a life-threatening food allergies.

Parental Perceptions of the Impact on the Child

Parental perceptions of the impact of childhood food allergy on the quality of life of a child have been measured in one quantitative study using the Children's Health Questionnaire (CHQ), a tool that has demonstrated strong internal validity and consistency in several disease categories (Sicherer, Noone, & Munoz-Furlong, 2001). Compared to previously established norms, parents of 253 children between the ages of 5 and 18 years with food allergies perceived a lower health-related quality of life for their children. Parents scored significantly lower scores in their perceptions of their child's

overall health, and this was magnified amongst parents of children who had other hypersensitivity disorders and multiple food allergies.

Parental Perceptions of Family Stress

Sicherer et al. (2001) measured parents' perceptions of the impact of a food allergy on overall family functioning and found that parents reported significantly more restrictions on their family activities, and more family tension than is the norm for these measures. Another study of the psychosocial needs of 17 families coping with anaphylaxis in a child reported that while mothers assumed the primary responsibility for the management of the child's allergy, fathers were less informed and less vigilant about protecting the child from an anaphylactic reaction (Mandell, Curtis, Gold, & Hardie, 2002). Several mothers also stated that they had remained in the homemaker role, at least in part to be available to meet the needs of the child with the food allergy, which could contribute to financial stress due to a reduction in family income (Gowland, 2001).

Parents reported that they were given insufficient information from their physician about their child's allergy at the time of diagnosis (Mandell et al., 2002), especially regarding allergen avoidance strategies and the administration of the EpiPen®. The gaps in crucial information and support were a source of stress for these families. Many stated that they received support and help in coping with the allergy from anaphylaxis support groups.

Parents also identified developmental issues as significant contributors to their anxieties and fears (Mandell et al., 2002). Normal developmental milestones in each age group, particularly those that involved increased independence on behalf of the child and less parental supervision, added to the anxiety experienced by parents. As children

matured, they were expected to become more involved in managing their allergy. One interesting finding was that parents of adolescent children were less focused on allergen avoidance and concentrated more on ensuring that the adolescent carried the epinephrine injector at all times. Teenagers, however, especially boys, may refuse to carry their EpiPens®, and spend increasing amounts of time away from home and unsupervised (Munoz-Furlong, 2003). The desire to blend in with their peers and avoid drawing attention to their food allergy could place this group at increased risk.

Parents reported a high level of protectiveness over their children, and tried to balance this against debilitating anxiety (Mandell et al., 2002). The restrictions placed upon children with food allergies was viewed by parents as having a negative impact on the child's social development. These findings were congruent with those from another study that looked at 153 parents' perceptions of the psychological burden of living with a child with a peanut allergy as compared with 69 parents of children with chronic rheumatological disease, utilizing the Impact on Family Questionnaire (Primeau et al., 2000). When comparing the two parent groups, parents of children with peanut allergy reported that their children experienced significantly more disruption in their daily activities and more impairment of their family and social interactions. Parents attributed many of their perceptions to their child's risk of death. Part of the stress associated with peanut-allergy stemmed from the need to exercise extreme dietary vigilance in order to avoid foods that contain peanut, and from the risk of a life-threatening allergic reaction.

Some parents described their patterns of coping with anaphylaxis in a child as oscillating from periods of high anxiety to reduced anxiety (Mandell et al., 2002). High anxiety was often precipitated by a recent accidental exposure to the allergen, the

discovery of new information about potential risks, or by developmental changes in the child that meant less parental supervision and control (e.g., starting school). Parents in another study said they tried to minimize the risks of anaphylaxis by achieving mastery over the condition and the associated dietary restrictions (Primeau et al., 2000). When they had to relinquish the care of their child to another, however, they sensed a loss of mastery resulting in considerable burden and stress. Major obstacles to coping included a lack of public understanding, and inconsistent and inadequate information on the safe management of life-threatening food allergies (Mandell et al.).

Perceptions of Adults and Children with Food Allergies

In addition to studying the perceptions parents held of their children, Primeau et al. (2000) compared the perceptions held by 37 adults with peanut allergy to 42 adults with rheumatological disease and found that the latter group experienced more disruption in their family relations and a greater financial burden associated with an increased need for medical care.

Gowland (2001) published a personal account of the stress of living for 40 years with a life-long allergy to peanuts. She identified several sources of stress including the need for constant vigilance in all matters involving food, inadequate food labels that are misleading or hide the presence of the allergen, the use of precautionary labelling on pre-packaged foods making it impossible to make an informed decision about the real allergen risk, social exclusion and exhaustion because of the careful preplanning required to participate in any social occasion or family gathering, and the difficulties associated with eating in restaurants or taking a vacation due to the lack of public education and support for individuals with food allergies. Gowland called for industry guidelines and

manufacturing standards that would protect allergic individuals from accidental exposure to allergens. Currently, in Canada, the Food Product and Labelling Committee of Anaphylaxis Canada continue to lobby the federal government with a Food Allergen Position Paper (Breen et al., 2002) containing recommendations that will address the concerns expressed by Gowland including labelling common allergens, disclosing hidden allergens, noting allergens in 'plain' English, and using precautionary labels responsibly.

Children with peanut allergy have reported a poorer quality of life, especially when compared to children of the same age with insulin-dependent diabetes mellitus (IDDM) (Avery, King, Knight, & Hourihane. 2003). Two disease-specific Quality of Life Questionnaires were developed and used to compare 20 children with peanut allergies (mean age of 9.0 years), with 20 children with IDDM (mean age 10.4 years). Children with peanut allergies expressed more fear of an adverse event (i.e. an allergic reaction) and more anxiety about eating, especially when away from home. They also reported significantly higher anxiety than children with diabetes about going on holidays, to birthday parties, and on public transport. Concerns and worries about going to school were similar in each group. Children with peanut allergies felt more restricted in their activities and more threatened by potential hazards in their environment. They felt safe, however, when they carried their epinephrine and when eating at familiar restaurants that catered to people with peanut allergies. The investigators concluded that the quality of life for children with peanut allergies was more impaired than for children with diabetes, but that the fears and anxieties they felt may have offered some protection, as they were more likely to practice vigilance in all matters involving food.

Food Allergies and Schools

The foregoing review of the literature supports the notion that anaphylactic reactions to foods are a medical emergency that must be appropriately managed in the school setting. The following examines the characteristics of food-induced allergic reactions in school, the allergy management behaviours of parents and school staff who must ensure the safety of children with allergies, and the legal considerations for managing students with life-threatening allergies in the school setting. There is no known available literature to date on the sources of stress for school staff that are faced with these responsibilities.

Characteristics of Food-induced Allergic Reactions in School

The characteristics of food-induced allergic reactions in school and preschool are not well documented. Two studies offered some insight into the nature and extent of the allergic reactions. One study was of a random sample of 100 participants of a Peanut and Tree Nut Allergy Registry in the United States who described 124 different allergic reactions that took place in school or preschool (Sicherer, Furlong, DeSimone, & Sampson, 2001). The 69 males and 31 females ranged in age from 9 months to 19 years, with a mean age of 5 years. Another study was of 132 parents of patients aged 3 to 19 years who were seen in an allergy clinic, and included 79 male and 53 female children (Nowak-Wegrzyn et al., 2001). In that study, 18 % of the children reported having one or more food-induced allergic reactions in school over the past two years, resulting in a total of 41 allergic reactions in school. In Canada, the Canadian Paediatric Surveillance Program (Canadian Paediatric Society & Health Canada, 2001) reported that 5 % of all cases of anaphylaxis occurred in schools or day cares.

A variety of foods have been implicated in allergic reactions in schools, but the most frequently reported foods were milk, peanut, egg, and tree nut (Nowak-Wegrzyn et al., 2001). The route of exposure to allergens included ingestion, skin contact, and possible inhalation (Sicherer, Furlong, DeSimone, & Sampson, 2001). For example, children might have been exposed to allergens, like peanuts, while making crafts or participating in school parties and celebrations, most often within the classroom. Delays in administering emergency medications (e.g., epinephrine) to the student were attributed to delays in recognizing symptoms, trying to contact parents first, not following the emergency plan, and unsuccessfully trying to administer the EpiPen® (Sicherer et al., 2001).

Allergy Management Behaviours of Parents

While studies show that the majority of parents have informed school personnel about their child's food allergy, many have failed to provide the school with epinephrine and to ensure that the school staff was properly trained to use the delivery device (Gold & Sainsbury, 2000; Nowak-Wegrzyn et al., 2001; Sicherer et al., 2000). Other parents neglected to ensure that there was an emergency action plan, with documented consent, in place at the school (Gold & Sainsbury; Nowak-Wegrzyn et al.; Rhim & McMorris, 2001). It is possible that parental knowledge deficiencies regarding the management of food allergies, previously reviewed, may have had an impact on their ability to help prepare schools in allergy management.

Allergy Management Behaviours of School Staff

In the summer of 1994, two children in Ontario died in supervised settings due to severe peanut allergy. In response to these events, Gold and others together with the

Canadian Society for Allergy and Clinical Immunology, provincial affiliates, and allergy organizations, developed a consensus position for the management of anaphylaxis in schools and other child care settings (Gold, Sussman, Loubser, & Binkley, 1996). This consensus position paper was presented as a working document that may be modified as future research dictates. The document formed the basis for the development of a handbook to guide Canadian school boards in the development of policies on the safe management of students with anaphylaxis in the school setting (Canadian School Boards Association, 2001). The handbook for school boards has guided the development of a protocol on anaphylaxis in at least one school board in the province of Newfoundland and Labrador (Butler, Henderson, Kufudi, Ricketts, 2003). However, the extent to which all schools and school boards have developed policies on anaphylaxis is unknown.

In the past, schools have attempted to manage children with food allergies by assigning them to designated “allergen-free” tables or rooms that are removed from the eating area used by other students. This solution has been considered discriminatory and did not take into consideration the psychosocial needs of the child (Gaudreau, 2000).

There has been considerable variation among schools regarding the management of students with food allergies (Boros et al., 2000; Rhim & McMorris, 2001; Watura, 2002). Two studies each surveyed a random sample of approximately 100 school principals in public schools in England and the United States. (Rhim & McMorris; Watura). A third study investigated parent reports of the first aid management of anaphylaxis in 7 schools and 35 preschools, representing 4173 students in South Australia (Boros et al.). Several deficiencies in the allergy management behaviours of school staff and principals were reported in these studies. While principals may have

been aware of the students with food allergies in the school, not every student had a written action plan that outlined the steps to follow in an acute allergic reaction. Approximately one-third to one-half of the students with food allergies had medications, including epinephrine, with them in school. There was considerable variation in the storage location for the emergency medications, however, and the majority of schools kept them in the main office. Depending on the physical layout of the school, the time it would take to retrieve the medication from the main office could cause a delay in treatment. In two of the studies, between 50 % and 60 % of the staff had received in-service education about food allergies and the correct emergency response. Only one-half of the schools in one study said that they felt confident they could deal with an acute allergic emergency (Watura). These schools also scored poorly on their knowledge of the signs and symptoms that indicate a student is having an acute allergic reaction.

Parents who reported on the management of anaphylaxis in schools and preschools stated that only one-half the students with food allergies were in schools that could provide the three essential elements of anaphylaxis management, that is, an action plan, emergency medications, and a teacher who was able to administer the medications (Boros et al., 2000). In all three studies, there was a paucity of school policies on prevention that enforced the removal of potential allergens from the school environment, thereby minimizing the risk for food allergic students.

A review of the preceding studies indicated that the allergy management behaviours of school staff who have students with food allergies were deficient in several areas: a) inadequate control /elimination of allergens in the environment, b) insufficient knowledge and understanding of preventive strategies, c) inability to recognize symptoms

of anaphylaxis, d) lack of emergency protocols for anaphylactic reactions, e) lack of available and/or accessible epinephrine, and f) inadequately trained staff.

Legal Considerations

It is generally understood that school boards in Canada cannot prohibit students with anaphylaxis from attending school based on their medical condition (Canadian School Boards Association (CSBA), 2001). In addition, the standard of care owed by an educator to a student is that of “a careful or prudent parent” (CSBA, 2001, p. 16). While the current state of law on this issue is not definitive, it does suggest that educators should take reasonable efforts to modify the school environment so as to prevent a student from experiencing an anaphylactic reaction in school, and they should also be prepared to respond appropriately to a medical emergency.

Recently, the Ontario government has introduced legislation to protect anaphylactic students. Bill 3 is a private member’s bill, spearheaded by Liberal MPP Dave Levac who is a former high school principal (Anaphylaxis Canada, 2005). The impetus for this bill began in 2003, when a high school student in Ontario died from anaphylaxis. She was allergic to peanuts, milk, and soy. On the day she died, she had eaten food from the school cafeteria that investigators believed may have been contaminated by one of the allergens. Even though she had been taught how to self-administer an EpiPen®, she did not have it with her on that day in the cafeteria. In response to this tragedy, Laurie Harada, Executive Director of Anaphylaxis Canada, reiterated that keeping a child with food allergies safe is a responsibility that must be shared by the child, the family, and the school. Whether or not a school has a good allergy management policy in place often depends on the principal’s commitment and

whether the parents are good communicators (Canada NewsWire, 2003). In reaction to the inconsistent, and at times substandard protection for children with allergies attending schools, Anaphylaxis Canada called upon the government to introduce Bill 3, also named *Sabrina's Law*, in memory of the student who died. Bill 3 is expected to come into force on January 1, 2006.

The Bill requires that every school board establish and maintain an anaphylactic policy, which must include, among other things, strategies to reduce risk of exposure to anaphylactic causative agents, a communication plan for the dissemination of information on life-threatening allergies, regular training on dealing with life-threatening allergies, a requirement that every school principal develop an individual plan for each pupil who has an anaphylactic allergy and a requirement that every school principal maintain a file for each anaphylactic pupil. (Anaphylaxis Canada, 2005, Bill 3, p.1)

Ontario's Bill 3 is the first proposed legislation of its kind in Canada, but it may be a catalyst to pass similar legislation in other provinces. In Newfoundland and Labrador, the results of a survey of school principals in 2000 indicated that 35 % of all schools had a policy on food allergies, and this number varied depending on the region of the province (Coalition for School Nutrition, 2001). The details of the policies and the relative consistency amongst policies in different schools were not assessed in the survey.

Summary of the Review of the Literature

There is a tendency amongst the general population to overestimate the prevalence of food allergy hence studies of prevalence based upon self-report should be viewed with caution. Nevertheless, prevalence rates as high as 6 to 8 % have been confirmed in children under 3 years of age, dropping to about 2 % in adulthood. The latest review of the epidemiological evidence on food allergy suggests that the prevalence is increasing and may even be as high as 3.5 to 4 % in adults. Food-induced anaphylaxis is the most severe form of food allergy and is potentially life threatening. To date, there is

no universally accepted definition of anaphylaxis and this has contributed to a lack of consensus about the prevalence, diagnosis, and management of this condition. While life-threatening food allergies that could potentially lead to anaphylaxis may not be as rare as was once believed, the prevalence of these conditions in the province is unknown.

At present, there are no known cures for food allergies. Individuals with allergies, particularly to foods such as peanut, tree nut, fish, and shellfish, must learn to prevent and manage this potentially life-threatening condition for the rest of their lives. Empirical research has provided valuable information to guide both the acute and long-term management of food allergies and anaphylaxis. It has also provided evidence about the situational circumstances and individual behaviours that could contribute to grave outcomes for people with life-threatening food allergies. There have been few studies located to date, however that describe the daily allergy management behaviours of individuals and families coping with this condition. Similarly, research into the sources of stress for children, teens, and families living with life-threatening food allergies is limited and should be further explored.

Children spend the majority of their childhood in school, and research has demonstrated that there is considerable variation amongst school staff in their approaches to safely managing students with life-threatening food allergies. A description of the current allergy management behaviours and sources of stress for school staff in this province would provide empirical support for recommendations to improve the school environment and, subsequently, the quality of life for families, children and teens with life-threatening food allergies.

CHAPTER III

Methods

This research study was a descriptive, exploratory, cross-sectional study employing both quantitative and qualitative research methods. The purpose of the study was to describe the allergy management behaviours and sources of stress for two groups in the population: a) principals of schools in the Kindergarten to Grade 12 school system in Newfoundland and Labrador, and b) parents of children and teens (or teens themselves) living with life-threatening food allergies and attending schools in the province.

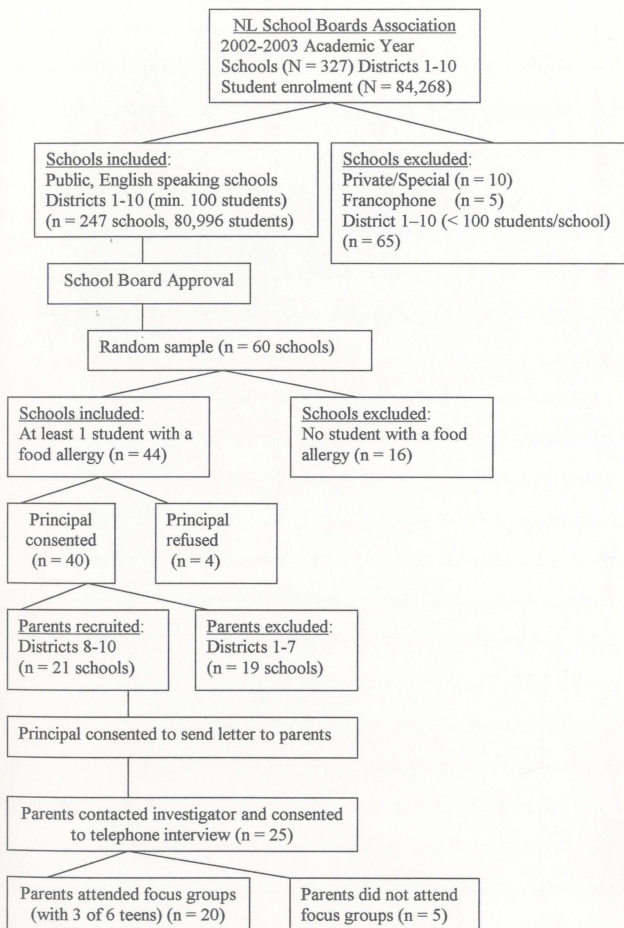
Study Participants

For the purpose of this study, school principals, and families of children and teens with life-threatening food allergies attending schools in the province were recruited. This was accomplished through a cooperative effort with the provincial public school system, and the process followed is outlined in a flow diagram (see Figure 2).

In the 2002-2003 academic year, there were 11 school districts and 327 schools in the Kindergarten to Grade 12 school system, representing 84,268 students (Department of Education, Government of Newfoundland and Labrador, 2003). Appendix B provides a map of the provincial school districts, as they were configured in 2002-2003.

A decision was made to exclude a number of schools from the study for the following reasons: a) All private schools and special schools (e.g., hearing impaired and first nations schools) were excluded because these 10 schools enrolled students who may differ from the general population of students in the public school system, and hence the results obtained from these unique groups may not be generalized to all schools;

Figure 2. Flow diagram of principals, parents, and teens recruited to the study.



b) the five schools in District 11, Conseil scolaire francophone provincial de Terre-Neuve et du Labrador were excluded due to language limitations of the investigator; and c) the sixty-five schools in the public school system (Districts 1 to 10) with total student enrolments of fewer than 100 students were excluded because the conclusions drawn from these small, intimate school environments may have been difficult to compare with other schools in the province.

A total of 247 English-speaking, public schools with a minimum enrolment of 100 students were eligible for inclusion in the study. Using a table of random numbers, a random sample of 60 schools was selected and the investigator contacted the principal of each school. In order to be eligible for continued inclusion in the study, a school had to have had at least one student with a life-threatening food allergy (severe enough to require an EpiPen®) in attendance during the current academic year. Of the 60 principals who were approached to participate in the study, 16 reported that they did not have a student with a life-threatening food allergy enrolled during the 2002-03 academic year, although they may have had students with food allergies in the past. Four principals who had students with life-threatening food allergies in their schools refused to participate citing a lack of time. Hence, the final sample comprised 40 principals (or designates) randomly chosen from Districts 1 to 10 who consented to be interviewed for the study.

The sample of parents and teens was accessed with the assistance of the school principals who participated in the study. Only principals of schools in Districts 8, 9, and 10 were approached to act as intermediaries in recruiting parents for the study. The sample of parents and teens was limited to those who lived in school districts 8, 9, and 10, due to their proximity to the investigator and limitations on travel to collect data for

the study. These parents and teens were drawn from the 21 schools in these three districts whose principal had consented to participate in the study. The principal made initial contact with parents of students with life-threatening food allergies through an information letter provided by the investigator. Parents who wished to participate were asked to contact the investigator to become part of the parent sample.

The final sample comprised 25 parents who had received the letter, responded to the investigator, were interviewed by phone, and were invited to participate in one of four focus groups. The purpose of the focus groups was to gather further details from parents that might support and explain information obtained in the structured telephone interviews. Twenty of the 25 parents attended focus groups; four parents could not attend due to conflicts with other commitments and one did not attend because she felt shy about participating in group discussions. Nineteen of the parents had young children; six parents had teenaged children with food allergies. Any teen with a life-threatening food allergy in Grades 7 to 12 in school districts 8, 9, or 10, whose parent consented to their participation in the study was invited to come to a focus group. Three of the six teens participated in the focus group discussions along with their parents. The others either had prior commitments or were reportedly too shy to participate.

Instrument Development

Two instruments were developed for this study: a) an Allergy Profile for Schools (see Appendix C) and b) an Allergy Profile for Parents (see Appendix D). The investigator examined the empirical literature related to the study objectives, obtained samples of existing questionnaires, and developed new questions to gather the information required for the study.

The Allergy Profile for Schools was developed by reviewing questions found in two questionnaires used in previous research on food allergies (Nowak-Węgrzyn et al., 2001; Rhim & McMorris, 2001). The investigator obtained written consent from McMorris and Nowak-Węgrzyn to use their instruments as the basis for developing an expanded questionnaire that measures the perceptions held by school principals in this province. The Allergy Profile for Schools is composed of three sections with closed-ended questions designed to gather information on: a) a general description of the school and the students with food allergies, b) the prevalence of specific food allergies, c) the approaches to identifying and managing students with food allergies, d) the education of school staff about food allergies, e) the availability of emergency medications, f) the maintenance of an allergy-aware environment, g) the emergency response activities, and h) the history of previous allergic reactions among students in the school. One open-ended question at the end of the interview invited principals to discuss issues that were a source of stress for schools with students who have life-threatening food allergies. The length of time to complete the telephone interview was 20 – 30 minutes.

The Allergy Profile for Parents was also developed by the investigator, with reference to a questionnaire utilized by Nowak-Węgrzyn et al. (2001) in the study describing food allergic reactions in schools and preschools. The purpose of the parent interview was to obtain background information about the child and about the day-to-day management of the child's food allergy. The Allergy Profile for Parents was composed of four sections with closed-ended questions designed to gather: a) basic demographic information, b) a description of the food allergic child, c) data on the prevalence of food allergies, d) personal and family histories of hypersensitivities, e) information on the day-

to-day management of food allergies, f) the past history of allergic reactions, g) the parental management of food allergies in school, and h) the parents' perceptions of the school management of food allergies. The telephone interview took approximately 30 minutes to complete, but this time could be extended considerably depending on the parent's desire to add supporting details.

Pilot Testing

Both instruments were reviewed by the advisory committee for this study and revised to ensure clarity in question wording and specificity in the response choices. Each of the instruments was pilot tested by two people who have considerable experience in the subject area. The Allergy Profile for Schools was pilot tested by a former primary/elementary school principal who later moved to a large school board and had had experience managing schools with students who have life-threatening food allergies. The second person was an experienced junior high school teacher who had helped to develop school protocols on the management of students with food allergies. The Allergy Profile for Parents was pilot tested by two parents of children with life-threatening food allergies who required EpiPens®. One was the parent of a teenager who was allergic to peanuts and tree nuts. This parent had worked closely with school boards in the province to develop policies on the management of food allergies. The other was a parent of an elementary school student who was allergic to shellfish.

The results of the pilot testing provided guidance on the content and wording of the questions asked. Suggestions from the parents and teachers were incorporated into revisions of the instruments. These revisions ensured that the intended meaning of the

questions corresponded with the respondent's interpretation of them. Pilot testing helped to protect both face and content validity of the instruments used in this study.

Questions for Focus Groups

All parents who participated in the study were invited to attend a focus group on living with life-threatening food allergies. Focus groups, as a research methodology, are well suited for exploratory studies where the investigator is interested in learning details about specific phenomena that may not be obtained using other methodologies. They are particularly useful when participants are relatively homogenous (Murray & Chamberlain, 1999) as was the case in this study. The focus group permits a group of individuals with a common experience (e.g., living with a child who has a life-threatening food allergy) to have a focused discussion guided by the interviewer.

The validity of this approach is sometimes called into question but can be improved if it is used appropriately for a problem that is suited to this method of data collection. Krueger (1994) identified several limitations of focus group interviews. One limitation may be a potential lack of control over the group interview. This concern was managed in two ways. First, the interviewer developed a set of questions to help guide the discussion and to address the five objectives for the study (see Appendix E). The questions were developed to gain an understanding of the complexities of food allergy management in schools within the broader context of the family's overall approach to living with a food allergy. The development of these questions was aided by the review of the literature and the information gathered from the parents in the prior one-on-one telephone interviews. The same set of questions was used for the four focus groups, all of which were moderated by the investigator. Secondly, the investigator has had experience

in managing other similar group discussions and was able to use these skills to keep the discussion focused. The investigator has also had graduate education in communication processes that enabled her to probe appropriately while moving through the questions.

The perspectives gathered from participants in focus groups can vary considerably depending on the composition of the group. Hence, the investigator conducted four separate focus groups in order to capture a variety of experiences from families living with food allergies. The large amount of data collected was carefully managed by audiotaping the discussions and later transcribing them for purposes of analysis.

Data Collection Procedures

The recruitment of principals and parents for this study was a multi-stage process (see Figure 2). In order to recruit school principals, and subsequently parents, for the study it was necessary to first contact each of the 10 school boards for permission to proceed. After obtaining ethics approval to conduct the study (see Appendix F), the investigator contacted the Executive Director of the Newfoundland and Labrador School Boards Association to obtain a complete listing of all schools and school boards in the province. He offered to contact the Director of each of the 10 school boards to explain the nature of the proposed research (personal communication, 2002). A copy of the proposed research and an introductory letter about the study were sent to the Assistant Director of Programs for the school boards in districts 1 to 10 (see Appendix G). Each school board approved the study unconditionally.

Once the list of 60 randomly generated schools was identified, a written explanation of the study was sent to the principal of each school (see Appendix H). A modified form of this letter was sent to principals in districts 8, 9, and, 10 as they would

subsequently be asked to assist with contacting the parents for the study (see Appendix I). After allowing time for principals to reflect upon the research request, the investigator telephoned each one to determine whether the school met the final criteria for inclusion (having at least one student with a life-threatening food allergy), answer questions about the study, and obtain verbal consent to participate.

After excluding the schools that did not meet the final eligibility criteria and the principals who did not consent to participate, there were 40 schools remaining in the final study sample. Principals who consented to participate in the study established a convenient time during which the investigator called back to conduct a telephone interview of the principal (or designate). Each principal was asked to prepare in advance of the interview to be able to report on the total number of students in the school, the number of students with food allergies, and the specific foods to which they were allergic. The investigator called back as many times as necessary to contact the principal for the interview. All interviews for the study took place between May 1 and June 23, 2003. This meant that principals were able to reflect back over the previous academic year when answering the questions in the interview.

Parents of children with life-threatening food allergies were contacted through the principals of the randomly selected schools from districts 8, 9, and 10. A letter was sent to these 21 principals and provided an explanation of the study, their involvement in the study, and a request that they deliver a second, enclosed letter explaining the study to all parents of students with life-threatening food allergies in the school (see Appendix I). Halfway through data collection, in an effort to recruit more parents for the study, a

second letter was sent to principals of the selected schools asking them to remind parents of students with food allergies about the study.

Parents of students with life-threatening food allergies were given an introductory letter and asked to contact the investigator if they would consider participating in the study (see Appendix J). They were able to contact the investigator by phone, e-mail, or through a stamped self-addressed envelope provided by the investigator. Parents who contacted the investigator and consented to participate were interviewed over the telephone (either immediately or at another convenient time) to obtain a history of the child's food allergy and information about the family's day-to-day management of the allergy. The parent interviews took place between May 1 and June 30, 2003. In answering the questions, parents reflected back over the child's life with a food allergy, and, specifically, over the previous academic year.

Any parent who consented to the telephone interview was also asked to participate in a focus group discussion with other parents of children with food allergies. The focus groups were held from September to November, 2003. Information gathered in the telephone interviews of parents suggested that the beginning of the school year was a time when they had a heightened level of concern about their child's food allergy, and would be most interested in contributing their ideas to a focus group discussion. Each of the parents in the focus groups were contacted on several occasions, by telephone or e-mail, in order to confirm a location, date and time that was convenient. Four separate focus groups were held, each comprising five to seven participants. Two focus groups were held inside St. Johns'; two took place in small communities in the eastern portion of the province.

Six of the parents in the study had teens with life-threatening food allergies. The original study proposal included a separate focus group for teens only but the small number and geographic distribution of the teens made this impractical. In the end, three teens accompanied their parents to focus groups and participated in the discussions with a group of other parents.

All focus groups were held at a time and place convenient for the participants. The discussion lasted approximately two hours and every effort was made to make participants feel at ease. All focus groups were audiotaped with participant consent. At the end of the focus group, each participant was given the opportunity to ask questions of the investigator related to food allergies in general, and each was given a package of information on asthma and allergies prepared by The Lung Association, Newfoundland and Labrador, a non-profit organization that provides education and support for individuals and families living with respiratory diseases, including asthma and food allergies.

Procedures for Data Analysis

Analysis of Quantitative Data

The quantitative data obtained from the interviews of principals and parents were analyzed using the Statistical Package for the Social Sciences (SPSS) (2003). The most appropriate method of data analysis was chosen depending on the level of measurement. Wherever interval data was collected, means were computed and compared. Descriptive statistics, analysis of frequencies, and cross-tabulations of variables were applied to the nominal and ordinal data collected from the questionnaires developed for this study.

Analysis of the Focus Groups

Immediately following each focus group, the investigator wrote field notes on the discussion paying particular attention to the main ideas that emerged and the overall mood throughout the focus group. Important quotes that best captured the meaning of the discussions were noted. In each subsequent focus group, new or unexpected findings were noted to permit verification in the upcoming focus group. Each focus group lasted approximately two hours, and the tapes were labelled with the date and location for future reference. A backup copy of each tape was made and stored in a secure location.

Either the investigator or another experienced transcriber transcribed each focus group discussion verbatim. The investigator then reviewed all tapes a second time to check for accuracy and to add missing data. Using content analysis, the investigator examined the transcripts for each individual question in the focus group and identified key words and phrases emerging from the transcripts. Coding categories were developed and all data in each transcript were coded. This process was repeated for each focus group using constant comparisons of similarities and differences in the various responses to each question. The coding categories were subsequently grouped under the key themes emerging from the discussions. For example, responses categorized as *shock*, *guilt*, and *feeling ill-prepared* were all grouped under the general theme: *Reaction to initial diagnosis*. Throughout the analysis, consideration was given to the frequency and extensiveness of comments so that the themes for which there were considerable discussion and consensus held more weight in the final analysis. Phrases and quotes that illustrated each theme were recorded.

In the next level of analysis, the investigator examined the emergent themes in light of the five main objectives for the study. The themes that were identified from the earlier analysis were grouped under the appropriate study objective. In the end, the results were considered a true reflection of the main themes arising out of the four focus groups in relation to the objectives of this study.

Ethical Considerations

Permission to conduct this study was granted by the Human Investigations Committee of the Faculty of Medicine, Memorial University of Newfoundland following a review of the research proposal (see Appendix F). A copy of the proposed research along with an introductory letter about the study was sent to each school board involved in the study. The proposal was approved unconditionally by each board.

Once the random sample of schools was generated, verbal consent to participate was obtained from each principal in the initial contact. A telephone script was used to obtain verbal consent to be interviewed for the study (see Appendix K). All completed questionnaires were coded to protect anonymity.

The parents in this study were contacted by the principal of the selected schools (see Appendix J). Voluntary participation was emphasized, and it was the decision of the parents whether or not to contact the investigator to inquire about the study. If a parent chose to contact the investigator, the investigator explained the study in detail and answered all questions. Verbal consent was obtained from the parent at the beginning of the telephone interview (see Appendix L). Completed questionnaires were coded to protect anonymity. Parents' decisions to attend one of four focus group discussions was completely voluntary.

Before beginning each focus group, and the nature and purpose of the discussion was further explained, and written consent for voluntary participation was obtained from all those in attendance (see Appendix M). Participants were notified that the session would be audiotaped to facilitate data collection. The participants were given the option to use a fictitious name, and the transcription of the data did not include any names or identifying information.

Parents who brought their teenaged children to the focus groups were asked to discuss the study with their children prior to attending. The teens were encouraged to ask questions and seek clarification about the purpose of the study from both their parents and the investigator. Written consent from the parents and written assent from the teens were obtained before commencing the focus group (see Appendix N).

All principals, parents, and teens were reminded throughout the study that their participation was voluntary and that they could discontinue their participation at any point during data collection. There were no known risks or benefits associated with participation in this study. Anonymity was protected and the names of the schools, principals, parents, and teens did not appear anywhere on the questionnaires. The master list of subjects and questionnaire codes, and the audiotapes of focus groups were kept in a secure locked location known only to the investigator. The data collected and the focus group transcripts were kept in a password-protected file which remained confidential to the investigator. The identity of the participants was protected in all research reports.

Each participant was offered a summary of the results of the study upon completion. Parents were given educational information and contact lists for community resources available to support families living with life-threatening food allergies.

CHAPTER IV

Findings

The findings from the study have been divided into three sections. Section one is a report of the findings from interviews with school principals, and is divided into three sub-sections: (a) a description of the school sample, (b) the allergy management behaviours of principals, and (c) the sources of stress for schools managing students with food allergies. Section two is a report of the findings from interviews with parents, and is divided into three subsections: (a) a description of the parent sample, (b) the general allergy management behaviours of parents, and (c) the allergy management behaviours of parents in schools. Section three is a report of qualitative findings from the focus groups, and is divided into three sub-sections: (a) the sources of stress for families living with food allergies, (b) the allergy management behaviours of teens and families, and (c) parental perceptions of the behaviours of school staff.

Findings from School Principals

Description of the School Sample

The final sample of schools in this study consisted of the 40 randomly selected English-speaking, public schools in the province during the 2002-2003 academic year, with a minimum enrolment of 100 students whose principals agreed to be interviewed, with a response rate of 91 %.

The total student enrolment in these 40 schools was 13,388 students, with a mean of 335 students per school as compared with a provincial mean of 328 students per school, for schools meeting the inclusion criteria. The schools that comprised the final study sample are comparable in size to other schools in the province.

The grade levels offered by each school in the province were divided into Primary (Kindergarten to Grade 3), Elementary (Grades 4 to 6), Junior High (Grades 7 to 9) and High School (Levels I to III). Several schools offered more than one grade level, and some schools offered all grades from Kindergarten through to Level III. Table 2 shows the distribution of grade levels in the province during the 2002-2003 academic year, and the percentage of each provincial grade level represented in the study. The distribution of grade levels in the study was comparable to the provincial breakdown. In both the province and the sample, primary/elementary grade levels were represented slightly more than junior high/high school grade levels.

Table 2

Distribution of Grade Levels Offered in Schools in 2002-03

Grade level	Sample (n = 40)	Province (N = 247)	% of provincial grade levels in the sample
Primary (K-3)	24	153	15.7
Elementary (4-6)	27	152	17.8
Junior High (7-9)	17	126	13.5
High School (I-III)	12	104	11.5

Note. Provincial data refers to all English-speaking, public schools, with a minimum of 100 students enrolled.

The school participants interviewed for this study included 36 principals and 4 designates all of whom were guidance counsellors. For the purpose of this study, this group will be referred to as *principals*. The median number of years that a principal had worked in the school was 5 years, with a range of 1 to 27 years.

Description of Students with Food Allergies

Out of the 60 randomly selected schools in the province, 44 schools (73 %) reported at least one student with a life-threatening food allergy severe enough to require a prescription for an EpiPen®, and several schools had more than one such student.

There were 112 students with food allergies out of a total of 13,388 students in the 40 schools included in the final study sample. This meant that 0.8 % of the students in the sample had life-threatening food allergies, with a mean of 2.8 students with food allergies per school. If this mean were to be applied to each of the 247 schools in the province, there would have been over 690 students with food allergies attending schools in 2002-2003. Most schools (77.5 %) had one, two or three students with food allergies, however, five schools had six such students, one school had seven students, and one school had 12 students with food allergies. There was no relationship between the size of the student enrolment and the number of students with allergies identified by the principal. Information was not gathered on the gender of the students with food allergies.

Principals were asked to identify which foods the students were allergic to. Some students were allergic to more than one food (see Table 3). Allergy to peanut was the most prevalent food allergy, followed by allergy to tree nuts, shellfish, fin fish, and egg.

Table 3

Prevalence of Common Food Allergens Among Students with Food Allergies (n = 112)

Food allergen	No. of students allergic to the food	Percentage of students allergic to the food
Peanuts	88	79 %
Tree Nuts	40	36 %
Shellfish	15	13 %
Fin Fish	13	12 %
Egg	13	12 %
Kiwi	5	4 %
Milk	1	< 1 %
Soya	0	0
Wheat	0	0
Other ^a	7	6 %

Note The sum of students allergic to foods exceeds the total (n = 112) because some students had more than one food allergy.

^a Other foods included chicken, banana, spices, chocolate, seeds, and unknown allergens.

Allergy Management Behaviours of School Principals

Identification of students with food allergies.

Students with food allergies were identified to the principal in a number of ways. In 31 of the 40 schools (78 %) the principal was informed about the student by the parents; six of these principals were also notified by the school nurse or through records received from the child's previous school.

Most schools in the province (80 %) used a standard poster to communicate information about the students with food allergies, such as their identity (often including a photograph) and the action plan/protocol to follow in the event of an allergic reaction. Principals were asked to describe the poster used in their schools and, in virtually all instances, they described an Anaphylaxis Alert poster that was developed by the Airways/Allergies Parent Support Group of The Lung Association (see Appendix O). Six of the 40 schools, however, reported that they had no posters for their students with food allergies and no other written mechanism for communicating information about the student. The staff was simply made aware, usually by parents, of the identity of the student and the food allergy.

School policies on food allergies.

The majority of schools (63 %) in the study had a district-wide written policy to guide the management of students with food allergies; a further 22 % used a combination of school and/or district policies/protocols on anaphylaxis. Determining consistencies between the various school policies was outside the mandate for this study. Six of the 40 schools reported that, to their knowledge, there was no formal school or district policy on food allergies.

An Individual Student Support Plan (ISSP) was completed for certain students in 27 of the 40 schools. An ISSP is a plan that is designed by a team of individuals from various agencies (e.g., health, education, family) to provide services and support to students in need (Department of Education, 2005). Most students with food allergies who had an ISSP were also physically challenged or had a learning need which was the impetus for the ISSP. Increased teacher workload was given as one of the main reasons for not completing ISSPs for students with food allergies alone.

In 34 of the 40 schools, the principal was primarily in charge of ensuring the safe management of students with food allergies, either alone or as part of a group of school staff. In the remaining six schools, the guidance counsellor or another teacher often assumed this responsibility, or else the person designated to this responsibility was not formalized.

Principals in virtually all schools, with one exception, reported that the role of the school nurse in managing students with food allergies was minimal. Many principals stated that the nurse's role had diminished and she no longer had time to collect information about individual students and their food allergies.

Staff education on food allergies.

In 29 of the 40 schools (73 %), the staff members were required to attend an annual education session on the management of students with food allergies. The annual education session was usually held near the beginning of the school year, often as part of a staff meeting. A summary of the frequency of staff education on food allergies, and the school staff in attendance is presented in Table 4.

Table 4

Patterns of Staff Education on Food Allergies

Staff education on food allergies (n = 40 schools)	No. of schools	% of schools
Frequency of staff education:		
Annually ^a	29	73
Periodically, not annually	8	20
Never	3	8
Staff members in attendance (n = 37 schools):		
Regular teaching staff	37	100
Substitute teachers	4	11
Bus drivers/office staff/custodial staff	12	32
Student Assistants	18	49

^a Two of the 29 schools offered staff education twice a year.

The three schools that did not provide any in-service education on food allergies to their staff included one elementary and two junior high/high schools. In addition, one other all-grade school principal offered education only to the primary/elementary teachers, as it was felt that older students could manage their own allergies.

Substitute teachers were not required to attend the in-service session, primarily because they were not expected to come to the school for this reason alone; they were reportedly informed through teacher register notes or by reading the posters on the door.

Many principals said that it was difficult to enforce the education of bus drivers because the in-service was held after school, at the same time most drivers were transporting students. In general, principals felt that the issue of educating bus drivers was an important one and asserted that, ultimately, school boards needed to decide who has the responsibility to educate bus drivers, and the power to enforce the expectation for emergency response preparedness.

Student assistants are school staff who assist teachers in the delivery of services to students with special needs, including physically and cognitively challenged students in

the school (Department of Education, 2005). If the in-service session was held after school, the assistants reportedly would often forego the education, as it would not constitute paid work, thus explaining the 50 % attendance rate.

Principals were asked to respond to a list of topics pertaining to food allergies, to confirm whether or not the topic was covered in the in-service session, and to identify who taught the topic to school staff (see Table 5). In the majority of schools, the school

Table 5

Food Allergy Topics Taught to School Staff (n = 37)

Food allergy topic	No. of schools	Person who taught the topic
Signs and symptoms of anaphylaxis	36	Nurse (36)
Triggers of an allergic reaction	36	Nurse (33) Parent & Nurse (2) Principal & Nurse (1)
Strategies to prevent a reaction	33	Nurse (21) Principal & Nurse (7) Parent & Nurse (3) Principal (1) Parent of allergic student (1)
Responding to an allergic reaction	35	Nurse (28) Principal & Nurse (4) Parent & (2) Principal (1)
Administering epinephrine (EpiPen)	37	Nurse (36) Parent & Nurse (1)
Descriptions of previous reactions	26	Parent of allergic student (17) Parent & Nurse (5) Nurse (3) Principal (1)

nurse taught all topics pertaining to food allergies to the school staff. Descriptions of the student's previous allergic reactions was taught most often by the child's parents, as they were best able to provide individualized information, though only 26 of the 37 principals included this topic in the staff education session. Comments from principals indicated that either parents were not invited or did not wish to be a part of the in-service session on allergies. Strategies to prevent an allergic reaction in a school, one of the cornerstones of anaphylaxis management, was the next least taught topic.

Creation of an allergy-aware environment.

Preventing allergic reactions by strict avoidance of the foods to which children are allergic is one of the cornerstones of anaphylaxis management. Many schools attempted to minimize the risk of accidental exposure to food allergens by imposing restrictions on the presence of these foods in the school environment. Principals were given a list of options and were asked about their participation in several activities aimed at creating an allergy-aware environment (see Table 6).

The results in Table 6 show that over 80 % of the schools carried out several specific activities to create an allergy-aware environment. Most principals (83 %) requested that all students refrain from bringing the food allergens to school but were quick to point out that the school should not be perceived as being totally allergen-free. Two of the schools requested that *only* the students in the same classroom as the student with the food allergy refrain from bringing food allergens to school. In one of these schools, two students had experienced an allergic reaction, both outside the classroom.

While almost two-thirds of the principals reported asking students not to bring foods that "may contain" the allergen to school, they acknowledged that this was a

Table 6

Participation in Activities to Create an Allergy-Aware School Environment (%)

Allergy-awareness activity	P/E ^a (n = 25)	Jr/High ^b (n = 15)	Total (n = 40)
All students to refrain from bringing food allergens to school	96*	60*	83
Only students in same class to refrain from bringing food allergens to school	4	7	5
Students to refrain from bringing foods that "may contain" allergens to school	72	47	63
Students to refrain from bringing food allergens on bus (34 schools have food allergic students travelling by bus)	91	64	82
School to refrain from selling known food allergens	96	73	88
School to provide allergen-aware eating areas	4	13	8
Students to refrain from using allergens in science and heritage fairs, etc.	88	53	75
Teachers to refrain from bringing food allergens to school to eat	92	67	83
School volunteers informed about food allergies	76*	27*	58
Substitute teachers informed about food allergies	84	60	75
School to refrain from selling known allergens in fund-raising activities	80	60	73
Students/parents to refrain from sending known allergens to school parties	100*	53*	83
School to periodically send out reminder letters/newsletters about allergies	100*	53*	83
School to place allergy-awareness posters and signs around the school	96*	33*	72
Other (Eg., assemblies, providing alternate snacks, label reading)	52	20	40

^a P/E are primary and elementary schools; ^b Jr/High are junior high and high schools.

* Significant difference existed between primary/elementary and junior high/high schools ($p = 0.05$).

difficult rule to enforce. Many of those who chose not to enforce this rule advocated, instead, teaching students with allergies to learn to avoid eating foods that were not safe.

Principals reportedly asked teachers to refrain from bringing food allergens to school (83 %). Even though three-quarters of the schools reported that they informed substitute teachers about food allergies, few of them had a standard mechanism for alerting them. The same held true for school volunteers who were expected to observe the signs in the school; there was no formal process for informing them about students with food allergies.

Because of the perceived differences in how schools manage younger students and older students with food allergies, a new variable was created. This new variable (a *functions* variable) was used to categorize the data according to whether the school functioned as a primary/elementary school or a junior high/high school. The purpose of this newly created variable was to examine the notion that schools managed younger students with food allergies differently than older, teenaged students. The new variable was used for some, but not all, of the data analysis.

The criteria to determine whether a school functioned at the primary/elementary or junior high/high school level were as follows. If the grade levels taught in the school included kindergarten to grade six, the school was deemed to be functioning as a primary/elementary school. Similarly, if grades seven to level III were taught in the school, it was deemed to be functioning as a junior high/high school. If the school taught students from both groups, then the grade level that the student with the food allergy was in was used as the basis for assigning the school to one of the two groups. Lastly, if there were students with food allergies in a school with both grade levels, then the school was

categorized as primary/elementary, since the youngest students with food allergies would determine the maximum level of vigilance in allergy management. Using these criteria, the sample was divided into two groups; 25 (60 %) were primary/elementary and 15 (40 %) were junior high/ high schools.

The data on allergy awareness activities were examined using the newly created variable to compare the frequencies of allergy-awareness activities in the two groups of schools. Where possible the Chi-square statistic was chosen, however, if one of the expected frequencies in the contingency table was less than 5, the Fisher Exact test was applied at a 0.05 level of significance. In almost all cases the frequencies with which both primary/elementary and junior high/high schools carried out allergy-awareness activities were the same. For five of the activities, however, there were significant differences between the two types of schools. Primary/elementary schools were more likely than junior high/high schools to ask all students to refrain from bringing the food allergens to school; to inform school volunteers about food allergies; to ask parents to refrain from sending food allergens to celebrations, parties, and graduations; to send out reminder letters throughout the year about food allergies; and to place allergy awareness posters and signs around the school. The principals from junior high/ high schools often commented that there was a "hands off approach" at this level, and that students were expected to take personal responsibility for their allergies.

Principals from 4 of the 40 schools reported that they did not participate in any of the preventative activities to create an allergy-aware environment listed in Table 6, except that two of the four schools posted a sign in the staff room to inform teachers of the students with food allergies. All of these schools were junior high/high schools, and

principals there felt the students were older and self-sufficient. Principals in two of these schools said that the parents of the students with food allergies supported this approach.

Availability of emergency medications.

According to principals, most parents provided the school with either one or two EpiPens®, with a median of two EpiPens® per student to be used in the event of an allergic reaction. Two schools requested three EpiPens® per student. In one school, which was located 40 minutes from the nearest medical facility, the parents were not required to make any EpiPens® available.

Table 7 provides a summary of the availability of emergency medications to students in school. In 95 % of schools in the study ($n = 38$), students with food allergies were able to carry their own EpiPens®. These percentages remained the same even when comparing primary/elementary to junior high/high schools.

Table 7

Availability of Emergency Medications in School ($n = 40$)

Availability of emergency medication	No. of schools participating	% of schools participating
Location of EpiPens® and back-up EpiPens®:		
Carried by student	38	95
Main office	20	50
Homeroom teacher's desk	15	38
Other (staff room, gymnasium, music room, guidance room)	6	15
Student permission to carry medication:		
Permitted, but not required	25	63
Required	13	33
Not carried by student	1	2
No medication available in school	1	2

In two schools, students did not carry EpiPens® because, in one case the student did not have an EpiPen® at school and, in the other case, the principal felt that the student in

Kindergarten was too young to carry it. When asked about the minimum grade level at which students carried EpiPens®, most principals reported that the decision was not based solely on the age or grade level of the student. Instead, in 26 of the 38 schools where students carried EpiPens®, the decision was based on a combination of parental consent and the behaviour and/or cognitive understanding of the student. In a small number of cases, the principal relied on the recommendations of the school nurse, family doctor, or the ISSP in deciding whether or not a student should carry an EpiPen®.

Approximately one-third of the principals responded that they had been in a situation where parents of students with life-threatening food allergies had *not* provided the school with emergency medications because either the parent had forgotten to bring an EpiPen® to school, or it had expired and had not been replaced. As soon as the parent was reminded of this by the principal, a new EpiPen® was usually supplied. In at least three instances, the parents could not afford to buy the EpiPen®, and the principal either purchased it, approached the Department of Social Services for financial support, or asked a local service club to assist with buying it. Six families reportedly resisted providing EpiPens® for the school because they argued that their child did not need to have one available at all times. Many principals asserted that the School Board should enforce a ruling that every student with a life-threatening food allergy has two EpiPens® available at school at all times.

Emergency response procedures.

In the event of an acute allergic reaction/ anaphylaxis in a student with a known food allergy, most principals (83 %) said that, since the school provided annual in-service education, *any* teacher in the school, including him/herself, would be expected to respond

and administer the emergency medications. In two junior high/high schools, it was unclear as to who would respond to an emergency, and the principals of these schools suggested that the student experiencing the allergic reaction or a friend might administer the EpiPen®.

If a student were to have an acute allergic reaction/anaphylaxis while at school, almost one-half of the principals said they would transport the student to the nearest medical facility by ambulance, and another one-third would transport the student in their own car. The remaining nine principals, primarily from rural areas, reported that they would call for an ambulance, begin to drive the student in their car, and arrange to meet the ambulance en route to the hospital. The decision to travel by car or by ambulance was influenced by the availability of ambulances, not by the distance the school was away from the medical facility. After removing three schools from the calculation that were unusually far away from hospitals, the mean length of time it took to travel from the school to a medical facility was six minutes, with a range of 1 to 20 minutes. One of the schools in which the allergic student had no EpiPens® was located 40 minutes from the nearest medical facility. Another school was located 55 minutes from medical care and the student had only one EpiPen® at school, due to the cost of purchasing a second one.

Principals were asked about their emergency response preparedness when taking students with life-threatening allergies on field trips. In 25 of the 40 schools, the homeroom teacher was expected to ensure that the emergency medication accompanied the student. In junior high and high schools, however, the responsibility for bringing the EpiPen® lay with the student with the allergy. In primary/elementary schools, a parent of

the student with the food allergy often attended the field trip and took responsibility for the EpiPen®.

Circumstances associated with past allergic reactions.

When asked whether a student had ever had a food-induced allergic reaction in school requiring an EpiPen®, 36 principals responded negatively. Two of the four remaining principals reported having witnessed one reaction at school, and two reported witnessing two reactions each. The environments and circumstances in these four schools were examined. Two schools, while very proactive in supporting an allergy-aware environment, were found to have *large* numbers of students with food allergies (i.e., six or seven students with allergies). The other two schools admittedly did not participate in the activities that create an allergy-aware environment. In the majority of anaphylactic reactions, the principals reportedly did not know how the reactions were triggered.

The incidence of anaphylactic reactions reported on school buses was low. Out of the 34 schools that had students with food allergies travelling to and from school on a bus, only two schools reported an allergic reaction. The principals did not know what had triggered the allergic reaction, but it was believed to be caused by foods other children on the bus had eaten for breakfast that somehow affected the student with the allergy.

Patterns of allergy management in the schools.

An analysis of the findings from the 40 principals in the study revealed that most of the deficiencies noted in allergy management were not dispersed throughout all of the schools in the study sample, but instead, were clustered within 10 specific schools. These 10 schools, 25 % of the schools studied, differed from the remaining schools in their

approach to managing students with life-threatening food allergies. Such differences may have placed students in these schools at a higher risk for potentially grave outcomes.

Eight of the 10 schools were junior high or high schools, and none of the schools had more than three students with food allergies. Virtually every student in these 10 schools had either one or two EpiPens® available, but one school did not have any medications for students with food allergies, and this school was 40 minutes away from a medical facility. A summary of the deficiencies in allergy management in these 10 schools is presented in Table 8.

Table 8

Patterns of Allergy Management Deficiencies in Schools (n = 10)

Deficiency in allergy management in schools	No. of schools
No/unclear food allergy policy/protocol	6
No process for identifying students with allergies	6
No written action plan	6
No annual staff education on food allergies	7 ^a
No allergy-aware environment	5
No emergency response plan for school staff ^b	5

^a Four of these schools held periodic staff education session on food allergies.

^b Emergency response was the responsibility of the student or was unclear.

Sources of Stress for Schools Managing Food Allergies

Principals were asked an open-ended question about their concerns related to students with life-threatening food allergies. A content analysis of their responses revealed three primary sources of stress experienced by principals: (a) balancing the rights of allergic and non-allergic students while creating an allergy-aware environment, (b) feeling uncertain about their abilities to handle the challenges of allergy management, and (c) coping with the additional workload associated with the safe management of students with life-threatening food allergies.

Balancing rights.

Many principals had concerns over their abilities to create an allergy-aware environment while balancing the rights of the non-allergic majority of the school community. Principals reported that they had received complaints from parents of non-allergic students about the food restrictions in the school. A common complaint was that peanut butter sandwiches could not be sent to the school; parents asserted that their children would not eat anything else for lunch. Principals were caught in the middle of the debate over food restrictions in schools. Many expressed empathy for the non-allergic community, yet recognized their responsibilities to protect students with life-threatening allergies. Ultimately, principals who had created an allergy-aware environment in schools believed that the health and safety of the student with the allergy came first.

Several principals felt, however, that some parents of students with allergies over-reacted and were unrealistic in expecting the school to ban multiple foods. Two principals expressed concern that children with food allergies needed to develop "life skills" that would enable them to function in the real world. The key, they said, was to find the right balance between teaching them and protecting them. There was a generally held sentiment among principals, including those who were proactive in creating an allergy-aware school environment, that improved public education about food allergies was the best way to gain the support of people who do not live with this condition.

In contrast to the parents of some non-allergic students, the non-allergic students themselves were reported to be supportive of their classmates with allergies, especially in primary/elementary schools and schools with low student enrolments where students were known to each other. One principal of a junior high/high school remarked that it

was both surprising and reassuring to find teenaged students complying so willingly with the food restrictions placed upon them. These principals asserted that students today are accustomed to growing up in a school environment where food restrictions are the norm. None of the principals were able to recall an incident of bullying of a student with a food allergy. One principal warned however, that while students are generally empathetic to the needs of children with food allergies, there is a limit to the restrictions they will tolerate. He stated, "Students are generally kind and compassionate, but at what point would the line be crossed – and there is a line!"

Feelings of uncertainty.

Some of the issues that were cited as causing stress among principals included: (a) worrying that a student might be accidentally exposed to a food allergen and have an allergic reaction in school, (b) feeling uncertain of their abilities to respond correctly in an emergency, (c) dealing with the legal ramifications of possible inappropriate responses to allergic reactions in school, (d) being located far away from medical assistance, (e) trusting that students will not bring food allergens into the school, (f) handling parents of students with food allergies who do not take the allergy seriously and/or do not fully disclose all information about the allergy, and (g) finding out by accident part-way through the school year that a student in the school has a severe allergy.

Principals expressed a need for more support in the form of clear, specific guidelines from the School Board on the management of students with food allergies. For example, some principals asked, "Do we need a doctor's certificate at the beginning of each school year? Do we need to ban foods from the whole school or just part of the school?" One principal recommended that a qualified individual be hired by the province

to follow all students with allergies through the school system. This position would need the support of the authorities and decision-makers in the Department of Education.

Increased workload.

The third source of stress that was mentioned by virtually every principal in the study was the increased workload and responsibility associated with the safe management of students with life-threatening food allergies. As more and more students have developed allergies, school staff reportedly have felt overwhelmed with the workload. "This is just one more thing that has been downloaded onto schools," said one principal. Another principal said that schools are becoming "mini hospitals" trying to deal with all of the health problems of students, including food allergies, diabetes, epilepsy, and other health conditions. Many reported that it was becoming increasingly difficult to teach the school curriculum while dealing with multiple health concerns in the classroom. Most principals felt that the teaching staff was working well as a team to try to meet these challenges, but that it was taking a toll on teacher stress levels.

Findings from Parents

Description of the Parent Sample

Letters of invitation were prepared by the investigator for participating principals to send to parents. The principals of schools from school districts 8, 9, and 10 identified a total of 75 students with food allergies severe enough to require an EpiPen® in the event of an allergic reaction. The 25 parents from these school districts who responded to the invitation to participate in the study represented 33.3 % of the eligible parents.

Twenty-four mothers and one father of children with food allergies were interviewed by telephone. For the purpose of this report, this group will be referred to as

either *parents* or *mothers*. Two mothers in the sample had two children, each with life-threatening food allergies. Each mother was interviewed about both children. Hence, the data collected refers to the experiences of 27 children in school districts 8, 9, and 10. These 27 children formed the reference group for the data collected from parents.

Description of Children with Food Allergies

The 27 children with food allergies ranged in age from 5 to 16 years, with a mean age of 9.3 years; 16 were males and 11 were females.

The children in this reference group were allergic to a variety of foods. Table 9 compares the prevalence of various food allergies amongst these 27 children with the overall prevalence amongst all school children from the school sample. There was a higher prevalence of peanut, tree nut, and shellfish allergies amongst children whose parents consented to participate in the study than was reported amongst all students with food allergies in the school sample.

Table 9

Prevalence of Common Food Allergens Among Children of the Parent Sample (n = 27)

Food Allergen	No. of children with allergy in parent sample (n = 27)	% of children with allergy in parent sample (n = 27)	% of students with allergy in school sample (n = 112)
Peanuts	23	85 %	79 %
Tree Nuts	18	66 %	36 %
Shellfish	5	19 %	13 %
Fin Fish	3	11 %	12 %
Egg	3	11 %	12 %
Kiwi	1	4 %	4 %
Milk	1	4 %	<1 %
Soya	1	4 %	0
Wheat	0	0	0
Other ^a	9	33 %	6 %

^a Other foods included peas, sesame seed, spices, coconut, and meats.

The slight discrepancies in the food allergies reported by parents and principals (see Tables 3 and 9) may be explained as either an oversight by the principal who was interviewed, or that he/she was simply misinformed.

Many children had more than one food allergy, which accounts for the totals in Table 9. The 27 children in the reference group had allergies to 64 foods. Children were diagnosed with food allergies between 6 months and 9 years of age, with a mean age of 3 years, 2 months. Hence, parents had lived with this condition for an average of 6 years, with a range of 1 to 14 years. The majority of children were diagnosed based on a combination of clinical symptoms, and skin and/or blood testing performed by an allergy specialist.

Parents were asked whether their children had a personal or family history of allergies and/or hypersensitivities (see Table 10). Over 80 % of parents reported that their children were allergic to environmental allergens such as cats, dogs, dust, pollens, feathers, mould, and smoke. As with personal history, allergies to environmental allergens were common among the extended family history. Over half of the children had one or all of eczema, asthma, and rhinitis, and these were also in their family history. A small number of children had other mild food allergies to milk, peas, egg, kiwi, and fish; one-third of the children also had cousins and other extended family members with food allergies. Other allergies in their personal and family histories included allergies to medications and wasp/bee stings.

Table 10

Personal and Family History of Allergy and Hypersensitivity (n = 27)

Allergies and hypersensitivities	Personal history		Family history	
	No. Children	%	No. Children	%
Environmental allergies	22	81	17	63
Eczema	18	67	11	41
Asthma	16	59	5	19
Rhinitis	16	59	5	19
Other food allergies (mild)	6	22	9	33
Other	4	15	5	19

*General Allergy Management Behaviours of Parents**Strategies to prevent an allergic reaction.*

Mothers were asked whether or not a health professional had ever taught them strategies to prevent an accidental exposure to a food allergen. Half the parents had been taught about cross-contamination and one third of parents had been shown how to read food package labels to identify food allergens. Most parents had not received any teaching from health professionals on how to ask questions about food preparation in restaurants, or how to prepare school staff to manage food allergies. Parents reportedly had taught themselves most of the prevention strategies, citing several resources such as the Internet, other media, and a parent support group of The Lung Association, Newfoundland and Labrador.

All parents had taught their children not to eat foods provided by their friends, as a means of preventing an allergic reaction. Approximately 70 % of the parents had taught their children about cross-contamination and how to read labels on packaged foods to identify food allergens. Parents of very young children who were unable to read reportedly taught them never to eat pre-packaged foods without asking another adult to read the food labels for them. Less than half the children had been taught how to inquire

about food preparation methods in cafeterias and restaurants even though they occasionally ate at these places during the school day.

Availability of emergency medications.

All of the children in the reference group for the study were prescribed EpiPens® to be used in the event of an allergic reaction. Parents reported having anywhere from one to six EpiPens® for their child, and the median number was three EpiPens® per child. Some parents also carried an anti-histamine as an adjunct therapy, but the EpiPen® was the primary medication prescribed for emergencies.

Twenty-two of the 27 children (81 %) were prescribed their EpiPen®(s) by an allergy specialist; the remainder received the prescription either from a family doctor or paediatrician. The mean age at which children were prescribed an EpiPen® was three and one-half years. While 19 of the children were prescribed their first EpiPen® at diagnosis, three children were delayed six months and another four children waited a year after diagnosis before getting a prescription for an EpiPen®. Some of the delays were not well explained, but one parent was initially advised by the doctor only to avoid the allergen.

Knowledge of proper EpiPen® administration.

Parents were asked, when their child was first prescribed an EpiPen®, in what ways, if any, had they been taught EpiPen® administration (see Table 11). Ten of the 25 parents were taught by the doctor who prescribed the EpiPen®, though half of them received just a verbal explanation of the device. Some of the parents who were referred to a nurse, or to a nurse and dietician, spoke favourably about the comprehensive education they received, including a demonstration of the proper use of the EpiPen® using a trainer that simulates the actual device, but without a needle. Three mothers, however, said that

nobody, including the doctor, explained to them how to administer an EpiPen®, so they taught themselves by reading the instructions on the package insert.

Table 11

Methods of Receiving Teaching on EpiPen® Administration Among Parents (n = 25)

Teaching received by parent on EpiPen® administration	No. of parents
Doctor gave verbal instructions only	5
Doctor gave verbal and written instructions, and demonstration	5
Referred to a nurse for allergy education ^a	5
Referred to a nurse and dietician for allergy education ^a	4
Pharmacist taught parent	3
No teaching was received by parent	3

^a In most cases the nurse also demonstrated the use of the EpiPen using a trainer.

Parents were then asked whether they felt they would *know how* to use an EpiPen® in the event of an allergic reaction in their child. Twenty of the 25 parents felt they knew how to use the EpiPen®; many of them were nurses who were accustomed to giving needles. Five parents, including both parents who had two children with life-threatening food allergies, stated that they felt unsure about how to use the device. Then parents were asked whether they *felt comfortable with the idea* of giving an EpiPen®. Again, 20 parents said that they would administer it, including this time the parents of two children with allergies. They went on to explain that it was “a matter of life and death”, and the fear of losing their child would motivate them to respond accordingly.

Most parents in the study reportedly had taught their child, the immediate family and the extended family how to administer an EpiPen® (see Table 12). The parents usually taught children over the age of 10 and their friends how to use the EpiPen®. Very few parents taught school staff about the EpiPen® because they either knew or assumed that the school nurse had already taught the teachers.

Table 12

Number of Children whose Parents Taught EpiPen® Administration (n = 27)

Groups taught EpiPen® administration	No. of children	Percentage of children
The child with the food allergy	20	74 %
Members of immediate family	25	93 %
Members of extended family	21	78 %
Friends of allergic child	6	22 %
Parents of friends of child	10	37 %
School personnel	9	33 %
Babysitter/Daycare personnel	15	56 %
Other (bus driver, brownies)	7	26 %

Accessibility of emergency medications.

Eighteen parents said that the cost of purchasing EpiPens® was covered by their personal health insurance plan, and three other parents' plans covered the cost with special authorization provisions. Four parents, including one parent of two children requiring EpiPens®, paid for the medication out-of-pocket as they did not have personal health insurance.

Some parents purchased more than one EpiPen® to enable placement in several locations where their children spent a lot of time. Table 13 summarizes the most common permanent locations for EpiPens® for the 27 children referenced by the parent sample. Most parents kept EpiPens® in the child's school bag or fanny pack, at school in the main office or teacher's desk, and at the child's home.

The parents of three-quarters of the children with food allergies reportedly took measures to ensure that the EpiPen® was accessible to their child almost all of the time. Six parents said that the EpiPen® was available most of the time, but not always. Several reasons were given to explain why parents might not have an EpiPen® available for their child at all times. Parents stated that, on occasion, they had simply forgotten to take the

Table 13

Permanent Locations for EpiPens® (n = 27)

EpiPen® location	No. of children	Percentage of children
Child's home	15	56 %
Child's school	17	63 %
Child's school bag or fanny pack	20	74 %
Babysitter/Daycare ^a	3	11 %
Homes of extended family	1	4 %
Home of child's friend	0	0
Mother's purse	7	26 %
Other (e.g., hockey bag)	2	7 %

^a Applies only to children of preschool age.

EpiPen® with them when leaving the house, that the child was not intending to eat anything, that the food allergen was easy to identify and thus easy to avoid, or that it had been such a long time since the child's last allergic reaction that the parents and child had become complacent. Amongst the children who failed to carry their EpiPen® at all times 50 % were teenagers; the parents of two teens said that their children did not think they needed to have the EpiPen® available at all times and refused to carry it.

Management of allergic reactions since diagnosis.

Almost half of the children in the reference group, six males and six females, had experienced an allergic reaction since diagnosis. Seven of the children had experienced one or two reactions, three children had experienced three or more reactions, and two children had experienced many reactions in the past, too numerous to count. There were a total of over 30 allergic reactions since diagnosis in this group, not limited to the teenagers in the study. All of the children who experienced reactions since diagnosis had known allergies to more than one food, and all but one had allergy to peanut, tree nut, or

both. Among the 12 children who experienced allergic reactions, almost all of them had concurrent eczema and environmental allergies, and three-quarters had asthma and/or allergic rhinitis.

Most allergic reactions took place in the child's home or in the home of a relative or friend. Other places where reactions took place were restaurants, grocery stores, airplanes, daycares, and schools. Most of the reactions were caused by cross-contamination of a *safe* food by an allergen or the accidental ingestion of a food that contained a known allergen. Only two children experienced allergic reactions at school; one of them had had numerous exposures and allergic reactions at school including reactions that took place on the school bus.

Even though all children owned an EpiPen®, it was administered for only 2 of the over 30 allergic reactions. In some cases, the reactions were considered by the parents to be mild reactions because the child had not ingested the allergen and had no breathing difficulties. In these cases, parents administered an antihistamine and waited to see if the symptoms would subside. The parents who chose instead to transport their children to hospital often reported that their children were given epinephrine in the Emergency Department. Many spoke of their anxiety of not wanting to give the EpiPen® or of not being sure whether they should have given the EpiPen® at the time of the reaction. Some parents vowed that if a similar allergic reaction were to happen again, they would definitely administer the EpiPen® to their child.

Allergy Management Behaviours of Parents in Schools

Identification of child with food allergy.

Parents chose a variety of ways to inform the school about their child's food allergy. Twenty-one of the 25 parents approached the school principal; 19 of these parents also met with the child's teacher. Only nine parents who met with the principal had also talked with the school nurse. The four parents who did *not* approach the principal about their child's food allergy had also done very little else to inform the school. Most parents reported that the nurse had no role in managing their child's food allergy. As one mother of two children with life-threatening food allergies stated, "I have never heard from the nurse since this all started. I did it all on my own. Never has a nurse come to ask me about my [children]."

Virtually every child had a poster/action plan in the school that identified the student and the allergy, and outlined the treatment for an allergic reaction. The Anaphylaxis Alert Poster (see Appendix O) produced by the Airways/Allergies Parent Support Group of The Lung Association, Newfoundland and Labrador, was used in almost all schools attended by these children. Only three children did not have a poster or action plan posted in the school; all were teens, one of whom also did not have an EpiPen® in the school.

Staff education on food allergies.

Parents offered a number of approaches that they had used to help educate the school community about food allergies, such as meeting with each teacher in September, giving oral presentations to students, writing letters to be distributed to parents in the school, inviting health professionals to give presentations at the school, placing posters in

the classroom, volunteering at the school to ensure a safe environment for their child, and educating school councils.

Strategies to prevent allergic reactions.

Ten parents reported that they provided all the foods that their children ate at school, with no exceptions. Half of the parents stated that they provided *some* of the foods for their children, but that their children also bought foods at the school cafeteria or nearby restaurants. Parents had reportedly checked out the menu served in school, and while many schools sold foods with precautionary labelling, parents instructed their children not to eat these foods.

When asked where their children ate their meals at school, all of the parents responded that their children ate with the remainder of the student population, either in their classroom ($n = 15$) or in the school cafeteria ($n = 10$). The children with food allergies were not isolated to a special allergen-free location in the school to eat their meals.

Availability of emergency medications.

Twenty-three of the 25 parents (92 %) had provided the school with at least one EpiPen® to be used in the event of an anaphylactic reaction in their child. The EpiPen® was either carried by the student in a school bag or fanny pack ($n = 9$), stored in the teacher's desk or main office ($n = 6$), or both ($n = 11$). The two parents who had not provided the school with an EpiPen® also did not have health insurance to cover the cost of purchasing the medication. One mother also believed that her child's history of delayed allergic reactions meant that even if the child was exposed to an allergen at school the allergic reaction would likely not begin until the child came home.

Parental Perceptions of Allergy Management in Schools

Parents responded to a list of topics pertaining to food allergies and were asked to identify who, to the best of their knowledge, had taught these topics to school personnel in the past. The majority of parents did not know who had taught school staff how to manage students with life-threatening food allergies. Many parents “assumed” or “believed” that the school nurse offered in-service education to teachers, but they did not know what topics were covered by the nurse. There was little or no communication between the parent and the school nurse, and parents were rarely invited to participate in staff education about food allergies.

Parents’ perceptions of other allergy-awareness activities ongoing in their children’s schools are summarized in Table 14.

Table 14

Parents’ Perceptions of Allergy-Awareness Activities in School (n = 25)

Allergy-awareness activity	No. of parents	% of parents
School periodically sends out reminder letters/newsletters about allergies	17	68
All parents and students asked to refrain from bringing food allergens to school	22	88
All parents and students asked to refrain from bringing food allergens to field trips, heritage/science fairs, fund-raisers and celebrations	20	80
Parents notified about planned events and celebrations involving food through newsletters	13	52
Bus driver aware of food allergy and trained to administer an EpiPen®	3 ^a	12

^a Only 10 of the 25 families had children who travelled by bus to school.

While most parents reported receiving newsletters about food allergies in the school, eight parents reported either that no written communication was sent out to students, or that they did not know whether or not it was sent. Similarly, the vast majority of schools banned food allergens from the entire school, but one parent said that the food allergens were prohibited only in the child's classroom; two other parents reported no attempts to restrict foods brought into the environment. Also, while one-half of the parents reported that they found out about planned events and celebrations involving food by reading the school's general newsletter, few were personally notified in advance about these planned activities. Without advance notification, parents were unable to prepare to provide alternate foods for their children.

Only one allergic reaction was reported to have occurred on a school bus. The bus driver in this incident was not trained to administer an EpiPen®, but the child's reaction subsided with no treatment.

Parents' general perceptions of schools.

When asked how well their child's school accommodated the food allergy, 75 % of the parents rated the school as excellent or very good, five parents rated the school as satisfactory, and one parent said the school was inadequate. The parent who rated the school as inadequate said that the principal thought that her young child needed to learn how to function in society and, therefore, permitted all students to bring peanut butter to school. Other reasons why parents did not rank schools as "excellent" included the cafeteria selling foods that "may contain" known allergens, protecting students with food allergies only when reminded to by parent volunteers, and schools still learning how to safely manage students with food allergies.

When asked how they would rate the receptiveness of other parents and students to requests from the school not to bring in certain foods, 80 % of the parents said the schools were either excellent (no resistance) or very good (minor resistance). Three parents rated the receptiveness of other parents and students as poor, and had personally been reprimanded by parents of non-allergic students because of the food restrictions in the school. There was a general sense that a quiet resistance existed amongst some parents of non-allergic students who sent food allergens to school despite the restrictions.

Parents were asked to rate, on a scale from 1 to 10, how safe they felt their child was while attending school with a life-threatening food allergy. A rating of 1 meant “*not at all safe*”, and a rating of 10 meant “*as safe as if the parent was there*”. The mean and median rating was 8 out of 10. When asked to explain the rating given, parents gave reasons like, “The school is as safe as it can be”, “It is a risk every time he goes out the door”, “It’s out of your control”, and “You don’t know what other kids will bring in”. Some of the parents who gave the schools higher ratings placed a lot of faith in their child’s own ability to manage the food allergy safely. One mother said, “My daughter is a teenager. She looks out for herself”. Another said, “I have trust in my son. He can take care of himself.”

Findings From the Focus Groups

Description of the Focus Groups

Four focus groups were conducted for this study, the participants having been recruited from the parent sample. There were 24 participants in total, 21 parents (20 mothers and 1 father) and 3 teens with life-threatening food allergies who accompanied

their parents to the focus group. All parents had one child with a life-threatening food allergy, except for two mothers each of whom had two children with food allergies.

Two focus groups were held in St. John's, each composed of six parents; one parent was accompanied by her teenaged child. The other two focus groups were held in small communities in the eastern portion of the province. One of these focus groups was composed of five parents; the other included four parents, two of whom were accompanied by teenaged children.

In total, there were five mothers of teens in the focus groups; the remaining mothers had children who were 11 years old or younger, with an average age of 8 years. There were twice as many male children as female children represented in the four focus groups, and the majority of children were allergic to peanuts and/or tree nuts. The findings from the four focus groups represented primarily the views held by mothers of children and of teens with life-threatening allergies to peanuts and tree nuts.

Sources of Stress for Families Living with Food Allergies

Coping with the diagnosis of a life-threatening food allergy.

When asked to recall their feelings at the time of diagnosis of their child's food allergy, virtually every mother began by recounting the details surrounding the first allergic reaction and the sequence of events that transpired thereafter. When the responses of mothers to the initial diagnoses were analyzed, three common themes emerged: (a) feeling shocked, (b) blaming themselves, and (c) feeling inadequately prepared to manage the allergy.

Feeling shocked. The children in this study were diagnosed with a food allergy at the time of the first allergic reaction or when the child was later brought to a specialist

physician for allergy testing. Regardless of the circumstances, the over-riding emotion felt by mothers was one of shock. Some said they were so shocked that they did not really absorb what the doctor had said to them until they went home and thought about the impact the allergy would have on their lives. One mother explained her response to receiving the diagnosis:

She [the allergy specialist] described it and she was saying, like, it's a nut allergy and everything like this. She showed me the EpiPen, you know, and kind of walked me through it a bit. But I never got the chance to actually do it, or anything like that. So when I got home, that was when it actually hit, because, okay, he can't have this anymore, or he can't have this.

Blaming themselves. Several mothers said that they blamed themselves for their child's food allergy because they had consumed a large amount of the allergen while they were pregnant. Whenever a mother broached this topic during a focus group, the body language and supportive one-word responses of the others indicated that most mothers could relate to this emotion. At the same time, they pointed out that their actions were the possible consequence of ignorance. Here is what three mothers had to say:

If I hadn't been a peanut lover, would she have ended up with a peanut allergy? I ate peanut butter every day that I was pregnant.

But, I always blame myself for it because I think I read it in a newspaper. And I nursed her, and everything that I loved she is allergic to.

And I went through the same thing – blaming myself – I shouldn't have had peanut butter... Then I got past that. I didn't do it on purpose – like yourself. I mean you did it because you were trying to be healthy, I mean – high protein!

Feeling inadequately prepared. Most mothers reported feeling inadequately prepared by health professionals to manage their child's food allergy. They did not know which foods to avoid, were not given nutritional counselling, did not know how to read a food label to identify a food allergen, were not educated about cross contamination, and

did not know how to respond to a medical emergency such as an anaphylactic reaction.

Two mothers described how ill-prepared they felt upon receiving the diagnosis:

I really like his specialist, however, I suppose it is all the same with all the health care now. They are in there rushed and they don't have time. And we were not referred to a dietician or anyone at that time, or anyone to teach us about how to use an EpiPen – although we did get that from our pharmacist because we knew him. But we kind of walked out and went, "Whoa! Now where do we go?"

I was told that it was serious and she could die, so I just cried. And then I went home and cried some more. Eventually I went to see [a nurse who provides education on allergies] and had a session with her. It wasn't a half-day, but I did have an hour or so with her.

Group Leader: So did you feel well prepared after that?

No. I don't think you ever do.

The part of allergy management that was least understood by virtually every parent attending the focus groups was the correct administration of the EpiPen®. Several mothers said that the doctor who prescribed the EpiPen® did not adequately teach them how to use it. Some mothers resorted to searching the Internet; others had received teaching initially from a local pharmacist. One mother described the education she received:

No, nothing! Basically, he more or less said, "You pull the cap off, read the instructions." They told me it must be administered in the thigh area, that much they did tell me. That's about it! And I came home and I read it.

Though few in number, those who felt well-prepared to manage their child's food allergy at the time of diagnosis had received comprehensive education from a team of health professionals including their own doctor, a nurse who specialized in teaching families about allergies and EpiPens®, and a dietician who taught them how to read food labels and avoid known allergens. One mother said that she joined a local parent support group for families living with food allergies and she learned a lot from other parents.

These mothers who felt well educated used the information they gained to teach their families and friends about food allergies.

Lack of confidence about food allergy management and the use of the EpiPen®.

Despite the fact that several mothers participating in the focus groups had been living with their child's food allergies for years, they remained confused about the best way to manage the allergy. Throughout the discussion, mothers repeatedly tried to verify their knowledge and seek confirmation that their assumptions were correct.

Mothers lacked confidence in their ability to respond to an anaphylactic reaction. Several of them recounted episodes when their children had allergic reactions and, even though they had an EpiPen®, they were afraid to use it because they weren't sure if they knew when and how to properly administer it. They opted instead to try to get their child to the hospital quickly. A couple of mothers reported that the medical staff in the Emergency Department chastised them for coming to the hospital with the unused EpiPen® in their hand. Looking back, some mothers realized that they should have administered the EpiPen® but, at the time, were unable to recognize the seriousness of the symptoms. The lack of confidence expressed by mothers is evident in the following direct quotes:

That's my biggest fear. Even now I experience it. I don't know when, if he is having a reaction, would I know what to do or would I get Benadryl or should I give him the EpiPen. That's how I feel.

I was told basically, "When in doubt – give it." And that time when we got to the hospital, they took her in and hooked her up right away, and they said that I should have administered it. They actually got mad at me. They said, "Never do it again or you're going to lose her."

I suppose I know how to use it, but to me you won't know how to use it until you actually do. I've got the EpiPen at home but I would rather drive to the Emergency and take my chances than use the EpiPen. I am kind of nervous about it, and unless it's hands on, I'm afraid to do it with her.

And I did it, and I thought I never would do it. I thought I would never delay – because you say you would do anything for your child! And I went to the hospital with the needle in my hand.

One of the reasons given by mothers for not knowing how to respond to an allergic reaction was the unpredictability of the reaction. As one mother said, “There’s no order to it”, and that made some mothers feel that they lacked control when faced with an allergic reaction. Mothers felt they had to be on guard and ready to respond in an instant or it could cost their child’s life.

A small number of mothers felt that even health professionals today were not well prepared to teach others to prevent and treat allergic reactions. They also asserted that if parents and health professionals did not have a solid understanding of the proper management of children with food allergies, how could we expect schools to adequately meet the needs of allergic students.

Struggling with ‘letting go’ of the child with the food allergy.

All parents struggle with decisions about the level of independence to give their children, but mothers in these focus groups said that the “normal” restrictions of childhood were compounded by their child’s food allergy. Even ordinary activities such as attending school, going to birthday parties, and visiting a friend’s house to play were associated with heightened levels of stress for these parents. When their children were young, many mothers insisted on accompanying them to all parties and events outside the home. At the very least, mothers called the parents who were hosting the party, even if they were complete strangers, to inquire about the foods and the methods of preparation.

Mothers recounted the difficulty of “letting go” and trusting another person to protect their child from accidental exposure to allergens, and to respond appropriately to

an allergic reaction. One mother recalled how she reacted when her child went to a friend's house:

Her friend's mother gets on the phone and says there's absolutely no peanuts. And then, like, I'm on edge, and I go, "Okay, calm down, relax!" Cause, I mean, when I know the parent, I'm still edgy, but when I know the parent is there and they are aware of it, I'm not too, too bad. I'm kind of mellowing out some. I feel sometimes like the kids are looking at me like I got ten heads.

Many parents also spoke of the injustice of the restricted lifestyle that has been imposed upon their children. Two mothers explained:

There's so much you can't enjoy. And I certainly don't want to sound remiss, and I don't think I am, but I finally have said, "Okay, let it go." As they get older – and she's eight – she's very verbal and she has her EpiPen, and that's what it's for.

But, like you got to let go – and it's hard! But I said to my husband, I said, "[Our son's] friends often go a lot farther than he can", and that's a sin.

Other mothers stated flatly that they simply would not permit their child to do certain activities, such as school trips or birthday parties, because they were not willing to accept the risks associated with these activities. One mother provided justification for her decision:

I've been told that I'm a neurotic mother. But, if the two of us go anywhere – to a house, or to school, or to work, or to emergency, and the only diagnosis they can label the two of us is 'neurotic mother', then that's great. They could put 'dead child' on it.

While this approach gave mothers peace of mind, some said it was diminished by feelings of guilt about the impact these restrictions may have on the child's future growth and development.

Impact on growth and development.

The composition of the focus groups included parents of children of various stages of growth and development. While mothers acknowledged that every stage carries

its own risks, the types of concerns expressed by mothers changed with the growth and development of the child, and parents anticipated the challenges that they will have to face as their child continues to grow up.

Mothers of young children worried primarily about their child's ability to protect themselves in all situations involving foods. In an effort to increase control over the risks associated with food, they taught their children specific rules about allergen avoidance.

One mother recalled:

I think it's an age thing though too. My daughter sat in class the other day and they were making up safety rules for the classroom. And she came home and said, "Mom, I can't believe they broke the most important safety rule, and no one thought of it but me!" I said, "What's that?" She said, "No nuts! No peanuts!"

Mothers of young children also looked ahead and worried about their children reaching adolescence. They expressed fear of losing control as their children move outside the home and they wondered how their children would react when they cannot participate in the activities of their peers. One parent revealed:

Knowing that, at some point, I am not going to be there to protect him. At his age now, I can still pretty much control his environment. But that terrifies me.

Mothers of teens also worried about the future for their children; they looked ahead to a time when their children will start to live independently and wondered about the impact their restricted childhood would have upon their ability to become a confident and independent adult. One mother expressed her concerns:

When it comes to social situations, he's just that much more reserved and he's shy by nature. He doesn't want to be different and lots of times he doesn't speak out. In some ways he didn't have to because we were there. Now, as someone who could be in the workforce or away at school in a couple of years, he almost needs a little nudge, you know. And how to do it safely? Like he's really comfortable in his own little world and being at home.

Other mothers of teens agreed that the current lack of control they have over the situations their children encounter, coupled with an adolescent attitude of infallibility, had contributed to family stress. One mother recounted a story about trying to educate her son's new girlfriend:

I said, "Hello, are you my son's girlfriend?" "Ah, yes." "Well, he's allergic to peanuts and, like, don't eat them if you plan on kissing him. But I know you are not going to kiss him anyway, so it's not really a problem." [Laughter]

Another mother questioned whether teens are able to self-administer an EpiPen®:

You want it to be internalized. And when he had the reaction to chocolate, when it came right down to it, I thought he could administer his own EpiPen. He told me he could, but he couldn't.

One parent of a teen pointed out that teens with allergies have to be selective about the types of summer jobs they accept. Any job involving the preparation or sale of foods may be unsafe, especially if the environment (e.g., restaurant, convenience store) sells the known allergens.

Feelings of isolation, exclusion, and embarrassment.

Mothers were intent on preventing the isolation and exclusion that sometimes accompanies food allergies. Three mothers relayed stories of being heart-broken when they discovered incidents at daycare, schools and parties whereby their young children were excluded and/or isolated because of their allergy:

He was at nursery school one day and I went there lunchtime just to check on him. I went down and it was sad. He was just a little boy over in the corner. I cried right there in front of them. I said, "My God, what a sin. Look what you have done with my baby!"

The hardest thing I find with her is when she goes to birthday parties and she wants to have the chocolate cake. And if we don't know what's in it, we can't give it to her. We can't take the chance. And then she's at daycare and people bring in ice cream and she can't have it. And she gets really upset.

I felt so guilty the first time I didn't bring my own food and I said, "Oh my God, I could die for him now," cause he said, "Mommy, why didn't you make me a muffin?" And I could have died – I felt so bad.

Most mothers acknowledged that, through public education and awareness, this type of isolation is less likely to occur in schools and daycares today. However, even teens with food allergies were, by necessity, excluded from activities involving foods, such as eating out in restaurants. When the teens that were present at the focus group were asked about this issue, they tended to downplay the feelings of exclusion. They expressed a sentiment of acceptance of their restrictions because, as one teen said, "It's just the way I grew up." Only one teen expressed frustration with his inability to eat peanut butter because all of his friends had told him that it tastes really good.

While teens seemed to be accepting of the restrictions imposed upon them by their allergy, they also did not want people, including their mothers, to draw attention to their allergy in public places. All of the teens said that they would rather not eat at all than have their mother call a parent at a party they are attending or confront a person in a restaurant.

Only one parent in the four focus groups made reference to her child being bullied by other children at school because of his food allergy. However, some mothers said that they, themselves, felt all alone at times in their struggle to help their family adjust to a life-threatening food allergy. Where possible, these mothers turned to other parents who were living with the same condition.

Feeling pressured to eat.

One of the biggest frustrations expressed by teens was when other people tried to force them to eat foods that had been prepared especially for them, even when the safety

of the food was questionable. This situation was encountered at the homes of family and friends, on school trips, and at birthday parties. For this reason, many of the mothers invested time teaching their children to be assertive when pressured to eat food. Teens said that they found this pressure particularly difficult to handle when the adult involved interpreted their refusal as disrespectful or unappreciative. One mother revealed:

A lot of our friends – they want us to think that they are trustworthy, that he trusts them because they are special. And they try to force him to eat in situations where he feels uncomfortable to eat. Like, they're saying, "You can trust me. There's no peanuts in this, so eat it."

A teen also described feeling pressured to eat:

She made it just for me, so I felt like I've got to eat it. But I didn't eat it because I didn't see it being made. I don't care if the Pope made it; I wasn't going to eat it.

Loss of a carefree childhood.

There was considerable consensus amongst mothers that children who live with life-threatening food allergies do not enjoy the same freedoms as other children.

As one mother recounted:

One day I sat down and someone said, "My God, your son is so mature, he's so careful." And I said, "But you know something, he's been robbed of his childhood – that carefree thing."

Mothers felt that their children spent much of their childhood worrying about all matters involving food, reading package labels, assessing their environment, and coping with the restrictions that are placed upon them. While all mothers acknowledged the fact that their children lived a sheltered life, especially when compared to their siblings and other children their age, a small number of mothers went even further to state that their child with the food allergy was not a *free person*. Two mothers conversed:

I find, cause we have a four-year-old son and [our daughter with the food allergy] is six, and it's like he's allowed to go here, he's allowed to eat anything he wants.

He's a free person.

Family and relationships.

While mothers in the focus groups did not identify specific marital problems associated with living with a food allergy, it was clear from the discussions that the responsibility for managing the child's allergy fell primarily upon the mother. She was the person who made accommodations for the food allergy so that the child would not be excluded, ensured that the EpiPen® accompanied the child at all times, read all labels carefully, and worked closely with the schools to improve allergy awareness. Then, if something went wrong, she was the one who was expected to have prevented the situation. Mothers told stories of driving long distances to get EpiPens® for their children, confronting stewardesses on planes who were about to serve peanuts, attempting to educate restaurant staff about cross-contamination, and defending the child's rights when confronted by parents of non-allergic children at school. If the child were to have an allergic reaction, the mother was more likely to respond and administer the EpiPen® because, reportedly, the husbands would panic and not know what to do.

Two mothers recalled:

The first time he had a reaction my husband panicked and he got my son all upset. And the next day my husband said to me, "How come you were so calm?" I said, "You panicked, you had them all upset. Someone had to do it!"

Because, my husband, you give him something and you say, "Now read the label and make sure it doesn't have peanuts in it." He says, "That doesn't have peanuts in it." He thinks because it's not chocolatey or nutty it doesn't have peanuts.

Other sources of family stress that were discussed included the reaction of siblings who felt ignored because mothers had to spend extra time with the child with the food allergy. While some mothers reported that their extended families were supportive,

others relayed stories of conflict because relatives did not take the allergy seriously and placed the child with the allergy in situations that could be potentially harmful.

One financial impact of this condition was evident in the response of some mothers who reportedly chose to work part-time, instead of full time, and accepted jobs where they would have the flexibility to attend school celebrations and field trips involving food. Though EpiPens® are expensive, and children with food allergies frequently require several of them, most mothers reported they had personal health insurance to cover the cost.

Two mothers relayed that they actually considered their child's food allergy when purchasing the family home. One family bought a home within walking distance of the school because they did not trust the bus driver to safely transport the child with a food allergy. Another family bought a home in a particular school district in order to avoid having to send their child to a school that had a negative reputation for managing students with food allergies.

Lack of public understanding and empathy.

Throughout the four focus groups, mothers referred to a pervasive lack of public understanding of the seriousness of food allergies, and this was viewed as one of the main obstacles to improving the lives of children with food allergies. Mothers frequently identified the parents of non-allergic children at school as the least informed and the least understanding group. Some mothers blamed this on the fact that the current in-service education in schools is directed towards teachers, students and, sometimes, bus drivers but not to other parents, the very people who pack the lunches and make decisions about the foods that are sent to a school. One mother felt that if more parents were educated,

they would be more careful and understand the ramifications of their actions for children with food allergies:

One woman was complaining that other students in school can't have peanut butter and she said, "What's the problem? Why are you babying these kids?" And then they gave the in-service to the parents and told them how long you have, and how many seconds you have, and what happens, and then they said they never knew any of this could happen to people. And when she went home, she realized!

Another parent recounted a story about verbal harassment from parents of students in the school who do not have food allergies:

I've had parents call me and, you know, just say everything to me over the phone because their child couldn't have a peanut butter sandwich at school. They said, "I'll do all I can to get peanut butter back in the school," and I said, "I'll do all I got to do to keep my child alive! You give your child a peanut butter sandwich, he gets his dinner. My child gets to go to the hospital!"

Parents of children with food allergies were both frustrated and hurt by the lack of empathy demonstrated by those who are not afflicted with this health problem. One mother expressed:

I get so mad, I get so angry, because my child could die from this. Some parents' attitudes are like, "Peanut butter is the only thing my child will eat" and I say, "I'm sorry, my child can die from this... You've got to understand. You can choose what you don't want to eat, but you can't choose what your child's got."

Mothers made a variety of suggestions for approaching this problem including increasing public education through the use of the media, lobbying a business or corporation to provide funding for a major public awareness campaign, forming parent support groups at schools, and taking advantage of every opportunity in the school year when parents are gathered together (e.g., concerts, orientation night) to educate the school community.

Fear of death.

All mothers were acutely aware that death from food-induced anaphylaxis was a possibility they faced every day. The mother of one of the oldest teens in the reference group alleged that the fear of death never goes away. Two mothers described their emotions:

But, in terms of life and death, that fear never goes away. All the little things that companies and schools might do. It's not going to give you any guarantees. It does ease your mind a little bit – you know. It's like having that gate at the top of the stairs or the car seat. But who says your child is not going to die in a car accident? But if you have them in the seat you feel better.

The fear of death – always living in fear. When he goes on his day and everything is normal it's okay. But when there's a change in routine, like going to a party or going to a movie theatre...and sometimes it's just a little change. But, right away it's, "Be careful, take your EpiPen, don't do this, don't do that!" "I know Mom." But then he's on his own!

Frustration with food manufacturers.

In general, parents and teens reported frustration with food manufacturers who add peanut and nuts to so many foods, and refuse to guarantee the safety of other foods that are produced in peanut facilities. While the issue of inadequate labelling was briefly discussed in the focus groups, the most important issue for most mothers was the lack of *safe* ice cream in this province. Every focus group spent time discussing the fact that their children could not eat ice cream, one of their favourite foods. Mothers had even lobbied distributors inside and outside the province to get a peanut-free, nut-free ice cream for their children.

Perceived inadequacies in schools.

Parents were asked to describe their *perceptions* of the allergy management behaviours of school staff. Mothers reported that there was considerable variation in the

school management of food allergies in this province, and that was a main source of stress for families living with life-threatening food allergies. Mothers identified the allergy management behaviours of school staff that created either a positive or a negative school experience.

Sixteen different schools were represented by the focus groups. At least four mothers from four different schools (25 %) reported on multiple incidents whereby the allergy management behaviours of school staff placed the child at risk and created a negative school experience. The majority of mothers could identify at least one negative school experience. In fact, some parents stated that every September, in anticipation of starting a new school year, they became very stressed about the safety of their child in school. One parent relayed:

I said to a parent one time, you talk about emotions, "Most of the time I cope with it really well, but then I find I have one spurt...Every September is usually the time. For about three weeks I cry!"

Several allergy management behaviours on the part of principals contributed to a negative experience for families of children with life-threatening food allergies. This included refusing to restrict food allergens from the school environment, or not adequately supervising food restrictions. Two mothers gave examples:

Well, the letter came home last year saying that they had to learn to function in society. And I told him, "No, it's not society – school is a controlled environment." I don't think he wants to take on the responsibility of calling it 'peanut-free.'

It's not supposed to be there and they might tell you that it is not, but it is there. I have seen it because I'm over to the school all the time. I've seen other parents walking around with [peanut containing] bars in their hands.

Principals who were reactive, instead of proactive, about managing students with food allergies created a lot of stress for parents. Two parents explained:

Well personally, I would like to move into the school. It is getting better, but the school is reactive, not proactive. It's very difficult to get anything done.

I've found that the teachers he has had, every one of them was good. It's the principal. He doesn't want to face the facts. He doesn't want to disturb anything. He is just hoping that the whole year will go along smooth.

Several mothers reported that principals and teachers did not understand food allergies or take them seriously enough. One exasperated mother said:

And mine have even had reactions over in the school and they still don't understand how severe it is. It is not like it didn't happen over there. It's happened!

Parents told stories of teachers who did not know where to find the EpiPen® and wasted valuable time emptying cluttered drawers trying to locate the EpiPen®. The mother's frustrated response:

And she was saying, "Oh, I know it's here somewhere." And I couldn't believe it. But obviously, in the classroom, you know, by the time she found it he would probably be curled up somewhere in a corner.

Teachers who acted as though food restrictions did not apply to them and continued to eat the food allergens in school until caught by a parent created undue stress, as did teachers who distributed candy that may contain known allergens to other students in the class.

Parents reported that when school nurses were inaccessible to parents and had limited involvement with the family, parents had no knowledge of the topics that were covered in staff education or the response of the school staff to the in-service. One mother, who was a nurse, could not understand why the school nurse did not become more involved in helping parents. She asserted:

You know, you'd think that the school nurse would have a directive for them to be more proactive in the schools – to have the programs ready and not leaving it to the parents.

A couple of mothers cited a lack of support at the school board level. When one mother approached a school about placing an allergy alert sign in the school, and the principal was not supportive of the idea, the mother went to the school board. She recounted:

I called the School Board and she said, "Well, try your principal one more time, and if you don't get any satisfaction come back to us then."

In some cases, the school experiences of parents were positive. There was a strong consensus that the principal's level of understanding of food allergies and his/her willingness to support families living with this condition were the most important factors that determined whether families had a positive school experience. Other supportive behaviours in a school principal included listening to the parent, asking for parental input into allergy management, maintaining open lines of communication with parents, giving the parent a feeling of control over creating a safe school environment, not permitting students to bring food allergens into the school, periodically reminding other parents and students about the seriousness of food allergies, and encouraging students to proactively educate others about food allergies. In general, parents responded positively to principals who were empathetic to their stress and were viewed by others as having the authority to make definitive decisions to protect the life of students with life-threatening food allergies. The following quotes from parents illustrated the impact of the principal on the parents' positive perceptions of the school:

Well, I have my son in [name of school] and I must say, it has been wonderful. I mean I have the principal and she'll call me.

So, the principal, sure enough, this year he called me before school started, "Can you come down and talk to me about [your son] before school starts?" He was very good and the school was great down there.

[The principal] told me that as the principal he is so comfortable with what he has learned that he is very, like, a focused man. Everything gets in here and he deals with it. He did it all himself – with the juniors and the seniors.

The behaviours of other people in the school environment reportedly had an impact on creating a positive school experience for families living with food allergies. These included teachers who were willing to listen and learn about food allergies, and school nurses who made an attempt to learn about the specific needs of a child and kept parents informed about the in-service education provided to staff about food allergies. When parents were kept informed about allergy management strategies ongoing in a school, they felt a better sense of control over the school environment.

At least six mothers identified the impact that a proactive group of parents can have on creating a positive school experience. These mothers had worked voluntarily to create changes that improved the lives of children with food allergies. As one mother said, “People say it can’t be done but it can, you know. We can make the environment safe.”

Sources of greatest stress.

As part of the focus group discussion, mothers were asked, out of all of the sources of stress, what aspect of living with a child who has a life-threatening food allergy was the *most* stressful. Four main issues were identified: (a) the perceived loss of freedom experienced by their children who live unusually restricted lifestyles, (b) the loss of control experienced by mothers over their ability to keep their children safe, (c) the stress associated with sending their children to school, and (d) the unrelenting every day stress of living with a condition that could end their children’s lives unexpectedly. One mother revealed:

It is mentally draining. Every day. Because every day there is a challenge. Every time they go somewhere, whatever. Every time you go to a new friend's house, go to a new school, a new classroom, you know, birthday parties, or over to your mother's house, or whatever! Everywhere you go you are always looking around and making sure.

Positive outcomes from living with stress.

Mothers and teens were asked to consider whether there were any positive outcomes from living with a life-threatening food allergy. While their initial reaction was one of scepticism, the participants identified several potential benefits. Mothers stated that children with food restrictions might eat a healthier diet and consider more carefully the foods they consume. They also reported that their children were more empathetic and compassionate to people living with a variety of health challenges, not just food allergies. Children with food allergies must learn to be assertive and some of their mothers believed that they might not succumb to peer pressure to the same degree as other teens. One mother said:

I think it's hard not to give into peer pressure for lots of other reasons. But if somebody tried to talk you into something, you'd probably be pretty strong in your beliefs – in who you are.

Mothers expressed pride over the accomplishments of their children. One mother reported that her child had used the food allergy as an opportunity to do public speaking at school. Another mother was proud that her teenaged son had successfully lobbied a bar manufacturer who was then planning to remove peanut-free bars from their manufacturer's list. The proactive approach taken by this teenager made his mother feel proud, but she said it was the *only* positive thing that has resulted from his food allergy.

Allergy Management Behaviours of Teens and Families

Became a "woman on a mission".

Mothers who felt ill prepared at diagnosis to manage their child's food allergy reportedly adopted certain behaviours in order to prepare themselves to care for their child. They sought out information on food allergies and turned to other mothers who had more experience living with this condition.

Some mothers relayed stories of personal transformation following an early incident in which their child had, or could have had, a serious allergic reaction. Two mothers described the incidents and how it changed them:

He had the shot once he got to the hospital, and then I knew the seriousness of it. And, from there I took a proactive approach, and found out more and educated him more, and scared the living daylights out of him, and talked to the school and things like that.

Anyway, I went in and spoke my opinion to the school and that was when everything changed – big time!

Another mother of a child with a severe peanut allergy reported on her reaction when she discovered, through her pharmacist, that she probably should have been given a prescription for an EpiPen®, but that her allergy specialist had elected not to tell her about this life-saving medication. She gave a graphic account of her response:

So then I made another appointment with the specialist and I said, "Why didn't you inform me?" And he said, "Well, we didn't want to send you out in a panic." And those were his exact words to me. And I said, "Send me out in a panic! My child could have died and I wasn't prepared!" So, after that I became a woman on a mission.

Most mothers reported that their personalities were not naturally aggressive or assertive, but that with their child's life at risk, they felt they had no other choice but to go to their defence. Two mothers disclosed:

You become assertive, like we say, because you have to. It's not your choice!

You do what you have to. You shed a few tears, and you continue on again.

Teaching children to be vigilant.

In response to the mother's perceived lack of control over their child's food allergy, virtually every mother placed an emphasis on teaching their child to exercise extreme vigilance in all matters involving food. At a very young age, children with food allergies were taught to read labels and inquire about food preparation. One mother recalled:

The first word he knew how to write, even before his name, was peanuts! He knew how to spell peanuts; he knew how to read labels. He went to Kindergarten and his friends would have something in class and he would be there reading to see if it had peanuts or nuts in it.

Mothers reported on the efforts they have made and continue to make to prepare their young children to be assertive and protect themselves against the uninformed general public. One mother of a young child explained how she taught her child to be assertive:

I told him, "You are an individual and you have the right to question any adult – I don't care who it is. But if they say the food has no nuts in it, you have the right – you are allergic and Mommy is not always going to be with you. You have the right to say to that adult, 'Please read the label!'"

Making decisions on risk-taking behaviours.

When mothers of children with food allergies were asked whether they ever took measured risks involving foods, the responses were an emphatic, "No! Never!" This group of mothers reported taking a cautious approach to all matters involving food. However, when questioned further, some mothers admitted to permitting their children to eat plain vanilla ice cream with precautionary labels on it. They qualified their behaviour

and explained that they only permitted their children to eat vanilla ice cream, and only while in their presence. Two teens in the group admitted that they, too, had taken a chance and eaten vanilla ice cream. They had never reacted to it in the past, and they rationalized that even though the ice cream now had precautionary labels, the actual composition and production process had not changed.

Even though some mothers had been advised by dieticians not to buy foods that contained 'natural flavours', they occasionally gave these foods to their children and hoped that natural flavours did not include an allergen. Incomplete and confusing food labels were other factors that may have placed their children at a higher risk for allergic reactions. One parent reported:

I have bought 100 % canola oil, brought it home – better check that list. When I checked the ingredients it said 'May contain peanut oil!'

As they talked further about the issue of risk-taking, mothers acknowledged that all normal every day activities encompass a degree of risk for children living with food allergies. In particular, one mother said that every time she takes her child to a different school to participate in a team sport, she is placing her child at risk because every school has different rules for keeping food allergens out of the school environment. Another parent pointed out that every time you travel and stay in a place that is far away from a hospital, you are placing your allergic child at risk.

One factor that influenced the risk-taking decisions made by parents and children was the length of time since the last allergic reaction. Parents and children began to doubt the child's allergy, and lowered their guard around food. One mother confessed:

Do you know what I know, and what I very openly acknowledge, is that the longer [my son] goes without a reaction, the slacker I get...the danger is not imminent. It's not really fresh in my mind and that bothers me.

Two of the three teens admitted that they did not carry their EpiPens at all times. One teen explained that it has been so long since his last reaction, he has started to think he is no longer allergic to peanuts. The other teen stated that since all previous allergic reactions have been delayed, and the teen claimed to eat the same “safe” foods at all times, there was no need to carry the EpiPen®. The third teen stated that he carried his EpiPen in his pocket at all times and it was “not a big deal”.

Learning to cope with travelling, eating out, and celebrations.

Travelling and eating out in restaurants were not common activities amongst this group of mothers. However, they acknowledged that their choice of restaurants was limited because many could not accommodate their child’s allergy. Cross-contamination and a lack of education among restaurant owners and servers led them to avoid eating out. The general consensus was that the reaction you receive in a restaurant varied depending on the server and the chef. More expensive restaurants were believed to accommodate food allergies better than other food establishments.

Travelling was reported as being very stressful for families living with a life-threatening food allergy. There was a general feeling of mistrust of airlines and a perceived lack of compassion for people with food allergies. Many stories were told by mothers of near-miss incidents in airplanes when stewardesses were insisting on serving foods that might have caused their child to have an allergic reaction. Some parents were advised not to fly, or to get off a plane because the airline personnel were unwilling to try anything to minimize the risk to their child. As with restaurants, there were inconsistencies between airlines. Mothers reportedly became “women on a mission” and used their assertiveness to defend the life and health of their child. One mother recounted:

The steward said, "We can't make that announcement. That wouldn't be appropriate." And I said, "Okay, we'll put it this way: When we're 10,000 feet up, is it going to be appropriate to land that plane faster than you can count? Because I carry three EpiPens, and yes I'm a nurse, but I'm not a miracle worker. You better land that plane pretty quick!" "Okay, we'll make that announcement."

Celebrations such as Christmas and Halloween were viewed as a significant source of stress for those living with food allergies. At Christmas, the joy of visiting family and friends was tempered by the fear and tension of wondering what types of foods would be served. Mothers stated they were often placed in the precarious position of not wanting to offend the host, while protecting their child. Halloween, which is normally a happy occasion for young children, was replete with fear and tension. Mothers warned their children not to eat anything until all of the allergenic foods have been removed. One mother even offered to pay her child for his treats so that she could discard all of the candy after he returned home.

Several mothers addressed the problems of attending local movie theatres when their children have allergies to peanuts and tree nuts, as these foods are commonly sold in theatres. Some mothers reported that their teens were not even permitted to go to a movie theatre unless a parent accompanied them.

Compensating for the inadequacies in schools.

In response to the perceived inadequacies in the way schools manage students with life-threatening food allergies, mothers tried many things to keep their children safe. Mothers, primarily of primary/elementary students, baked foods for school parties and celebrations so that their children would be able to participate fully in the activities. They provided teachers with alternative snack foods to be used as substitutes for unplanned activities involving foods. They volunteered to supervise at school parties and outings,

and often tried to arrange their work schedules so that they could accompany their children on field trips. Whenever they went into their child's schools, they monitored the environment and looked for potential risks, such as food allergens that had been brought to school by students and teachers. Two mothers reported that they trained their children's bus drivers annually because the school would not do it. Overall, there was a pervasive feeling of a lack of trust towards schools where parents had encountered problems in the past pertaining to food allergy management.

Mothers felt it was imperative that a universal policy/protocol for the management of students with life-threatening food allergies be developed for this province. The variability in school response to this growing health problem has placed students at risk and increased the level of stress experienced by their families. One parent pointed out that the law places a duty of care upon schools to protect all students, including those with life-threatening food allergies. She remarked:

Well, my guess would be that while that child is in school, even if it meant that the school board is responsible for getting an EpiPen or to have access to one, because at the end of the day, while the child is at school there is a duty of care – you are standing in for the parents, right? So legally there are some obligations of safety there.

The absence of provincial standards on the management of students with life-threatening food allergies had left parents with no choice but to negotiate with teachers and school administrators every year. One mother summed it up when she said:

But that's what the government needs to do for all of Newfoundland, because now it comes down to whoever the principal is. You're at the mercy of the school principal!

CHAPTER V

Discussion

The findings presented in the preceding chapter will be discussed in relation to each of the five study objectives.

Number and Characteristics of Children with Life-threatening Food Allergies

One of the objectives of this study was to gather evidence on the scope of the problem of children living with life-threatening food allergies by describing the number and characteristics of a sample of students with allergies attending public schools in the province of Newfoundland and Labrador.

Number of Students with Food Allergies

In this study, the prevalence rate of food allergies severe enough to require a prescription for epinephrine in students from 40 English-speaking, public schools was 0.8 %. This prevalence rate is likely an under-estimate of the true prevalence of life-threatening food allergy amongst children in this province for the following reasons.

First, the absence of a universally accepted definition of anaphylaxis has been known to impede the diagnosis of food-induced anaphylaxis (Fogg & Pawlowski, 2003; Sampson et al., 2005). Hence, there were likely students with life-threatening food allergies attending schools at the time of the study who, due to confusion over the diagnosis of food-induced anaphylaxis, were not prescribed an EpiPen® by their doctor, though they may have experienced severe allergic reactions in the past. These students would not have been known to the principals who provided the information for this part of the study.

Secondly, interviews with principals revealed that many schools had not established policies or mechanisms for identifying students with food allergies; hence, there were likely students diagnosed with life-threatening food allergies who carried EpiPens® but were not known by the principal and were omitted from the study. Accordingly, the findings of this study may be an underestimate of the true prevalence of life-threatening food allergies amongst school-aged children in this province.

This study aimed to describe *only* those students who had life-threatening food allergies that required a prescription for an EpiPen®, and did not include students who had milder forms of food allergy. If one were to consider all forms of food allergy then the overall prevalence rate would likely have exceeded 1 % and been closely aligned with the results from the Canadian Community Health Survey (CCHS) (CCHS, 2003) which reported that 1.2 per cent of individuals between the age 12 and 18 years in this province had been diagnosed by a health professional as having a food allergy. These rates are lower than the recent estimates that between 3.5 % and 4 % of Americans have food allergies (Sampson, 2004), however, the self-reported survey data used to formulate these high prevalence rates of food allergy are notorious for providing over-estimates of the scope of the problem (Boros et al., 2000; Bjorksten, 2004; Sloan & Powers, 1986). The one Canadian study that measured *and confirmed* the prevalence of peanut allergy amongst children in public schools in Montreal provided prevalence rates of between 1.0 % and 1.5 % (Kagan et al., 2003), which correspond more closely to the results of this study.

This study provides evidence to suggest that, when compared with previous similar research, the number of students diagnosed with life-threatening food allergies

attending schools in this province has increased. In 2000, the Coalition for School Nutrition (2001) found 1.3 students per school with food allergies severe enough to require an EpiPen®. In the 3 years since that study was conducted, the mean number of students per school with life-threatening food allergies has more than doubled from 1.3 to 2.8 students per school. In fact, the average of 2.8 students with life-threatening food allergies per school found in this study is equivalent to the average found in St. John's area schools in 2000, schools that held approximately 100 more students than in this 2002-2003 sample. Thus, even with declining student enrolments, the mean number of students with diagnosed food allergies per school remained at 2.8 students, lending further support for a trend towards the increasing prevalence of this problem. Some of the increase in reporting of food allergies may also, however, be related to an increased awareness of the problem. For example, the primary/elementary school that reported 12 food allergic students was very proactive in identifying and protecting such students.

Number of Schools Affected

Almost 75 % of the schools in this study had at least one-student with a life-threatening food allergy; most of them had between one and three students with allergies, and several larger schools had more. This finding is slightly lower than the reports from two studies of schools in the United States that reported 86 % and 96 % of schools had at least one student with a food allergy (Rhim & McMorris, 2001; Nowak-Wegrzyn et al., 2001), but both of these studies included all forms of food allergy from mild to severe. When one considers that this study was limited to students with severe life-threatening food allergies, the results suggest that the management of students with food allergies is a challenge that is shared by the majority of schools in the province.

Characteristics of Allergies in Children and Teens

The characteristics of the allergies in children and teens in this study were similar to those reported in previous research on children with food allergies. The food allergens most commonly identified by both school principals and parents of children with food allergies in this study were peanuts, tree nuts, shellfish, fin fish, and egg, which is consistent with the epidemiological evidence on the most common food allergens (Sampson, 2003, 2004). Milk allergy is also prevalent among young children but was not found in this study, perhaps because this study focused on school-aged children and many children with milk allergy develop tolerance before starting school (Sampson, 2004). Many children suffered from multiple food allergies which is not uncommon amongst hypersensitive individuals (Sampson, 1996).

The personal health histories of the children in the reference group from the parent sample indicated that 80 % had environmental allergies and over 50 % had one or more of eczema, asthma, and allergic rhinitis. Similar hypersensitivity reactions were reported in family members of children with food allergies. One-third of them also had cousins and other extended family members with food allergies. These findings were consistent with the hypersensitivities commonly reported in individuals with food allergies (Sampson, 2004).

Histories of Food-induced Anaphylactic Reactions

There are no precise estimates of the incidence of food-induced anaphylaxis. Although determining this incidence was not one of the objectives for this study, 12 children from the parent sample had experienced allergic reactions since diagnosis, and many had experienced multiple reactions. These allergic reactions occurred in children

of all ages, and equally among both genders in the group. The reactions were not limited to teens, as might have been expected according to Bock et al. (2001), however, the number of teens in the study was too small to draw conclusions.

Descriptions of the individual and situational factors associated with the allergic reactions reported by parents were of interest. All of the children, except one, had known allergies to more than one food, including allergies specifically to peanut, tree nut, or both. Most allergic reactions occurred at home or in the home of a relative or friend, which is consistent with that reported in the literature (Dibs & Baker, 1997). Two-thirds of the children who experienced allergic reactions had a history of asthma and/or allergic rhinitis; virtually all of them had histories of eczema and/or environmental allergies. All of these individual factors are known to increase the risk of recurrent anaphylaxis (Cianferoni et al., 2004).

Allergy Management Behaviours of School Staff

Several studies have examined the school policies and mechanisms that are in place to manage students with food allergies (Nowak-Wegrzyn et al., 2001; Rhim & McMorris, 2001; Watura, 2002). This study expanded on the existing research in that it examined, in detail, the perceptions held by *both* school principals and parents of children with food allergies regarding the allergy management behaviours of school staff. Comparisons of these perceptions with one another provided yet another level of insight into the congruence in parents' and principals' perceptions of the approaches taken by schools to manage students with life-threatening food allergies.

Overall, the majority of schools in the province reported that they were meeting the needs of students with life-threatening food allergies. Relative to the three essential

elements of anaphylaxis management described in an earlier study, that is, an action plan, emergency medications, and a teacher who was able to administer the medications (Boros et al., 2000), schools in this province performed well. Over 90 % of the students with food allergies in this study (involving 80 % of the schools) attended schools that provided these three essential elements, as compared with only 50 % of students with food allergies in the study by Boros et al. One possible explanation for this may be that over the past 5 to 10 years there has been a concerted effort by some parents in this province to become proactive in school allergy management, part of which resulted in the development of a protocol on anaphylaxis (Butler, et al., 2003) that was adopted by one large school board in the province, and possibly used as a model for allergy management policies in other provincial school districts.

It may be argued, however, that there are more than three elements to consider in a comprehensive allergy management strategy for schools. The requirements outlined in Ontario's proposed Bill 3 (Anaphylaxis Canada, 2005) provide a comprehensive allergy management strategy which will form the framework for discussing this study's findings.

Allergy Management Policies

Any comprehensive allergy management strategy, such as the one proposed in Bill 3 (Anaphylaxis Canada, 2005), requires that every school board establish and maintain a policy on anaphylaxis. While 85 % of schools in this study reported having a policy on food allergies, as compared with only 35 % reported in 2000 (Coalition for School Nutrition, 2001), the mothers who participated in the focus groups asserted that there was still considerable variation in the school management of children with food allergies, and that this was a major source of stress for families. Close examination of

these policies was outside the mandate for this study, but mothers reported inconsistencies in approaches to food allergy management in several schools in the province.

Approximately 85 % of principals stated that they were the person on staff responsible for enforcing the school policies on food allergy management, either alone or as part of a group of school staff. While parents concurred with this assessment, they went even further and explained that the behaviour of the principal regarding allergy management, in particular his/her level of understanding of food allergies and empathy for families living with this condition, was a major factor that influenced whether or not the family had a positive or negative school experience.

Identification of Students with Food Allergies

One of the first steps in allergy management is the identification of students with food allergies. Ontario's proposed Bill 3 suggests that it is the obligation of the parent to inform the school about the child's food allergy (Anaphylaxis Canada, 2005), and this was the case for 80 % of the principals interviewed in this study. This finding was consistent with parental reports, although the majority of parents said they also informed the child's teacher about the allergy.

Individual Action Plans/Protocols

Every child with a life-threatening food allergy should have an individual action plan in place at school (Anaphylaxis Canada, 2005). Both the parents and principals in this study (over 80 %) employed a standard poster in the school that included information on the identity of the child, the type of allergy, avoidance strategies, and an action plan/protocol to follow in the event of an allergic reaction. This number was similar to

the 86 % of children reported by Nowak-Wegrzyn et al. (2001), and much higher than the 16 % of students who had written action plans in another study of school readiness for children with food allergies (Rhim & McMorris, 2001). The three children in this study who did not have a written action plan/protocol in school were teens; this was part of a trend towards decreased involvement by schools and parents when children with food allergies reached adolescence.

Part of an individual action plan for anaphylaxis includes the availability and use of emergency medications (i.e. EpiPens®), the first line of treatment for food-induced anaphylaxis (Anaphylaxis Canada, 2005). Principals in this study reported that virtually every student with a food allergy had at least one, and often two EpiPens® available in school. This finding was consistent with the reports from parents of children with food allergies in this study, and slightly better than the results of earlier similar research on schools by Nowak-Wegrzyn et al. (2001) who found that 84 % of students had medications available at school.

Approximately one-third of the principals in this study reported past experiences involving students with food allergies attending school *without* an up-to-date EpiPen®. According to these principals, parents said that they either forgot to provide the EpiPen®, could not afford to purchase an EpiPen® for their child, or that their child did not need an EpiPen® in school. Principals felt that school boards needed to become more involved in establishing policies on the minimum mandatory number of EpiPens® a child with an allergy must have available at school. Their concerns are supported by the result of previous research which suggests that when the parents do not provide the school with epinephrine and the staff are not properly trained to administer it in an emergency, the

student is placed at an increased risk for negative outcomes in the event of an allergic reaction (Nowak-Wegryzn et al.; Rhim & McMorris, 2001).

In virtually every school in the study, the principal reported that students with food allergies, at any grade level, were able to carry their own EpiPen®; the decision to allow this depended on parental consent and the student's behaviour and cognitive ability to handle this responsibility. Only 75 % of the parents who were interviewed for the study concurred with this approach, however, and some felt that their child was too young to be given this responsibility or that their child did not even need to have an EpiPen® available at school. These types of misunderstandings amongst parents and principals must be addressed by health professionals. Since research has shown that delays in the administration of epinephrine are associated with fatal outcomes (Sampson, 2003; Simons, 2004), permitting students to carry their own EpiPens® is crucial since school staff would not waste valuable time trying to locate the life-saving medication in an emergency. This finding also demonstrates that schools in this province are more advanced in this area than schools in the United States where less than 20 per cent of students carried their own epinephrine (Nowak-Wegrzyn et al., 2001; Rhim & McMorris, 2001), due perhaps to the increased efforts on behalf of groups of parents in this province to educate school staff about the safe management of food allergies.

Consistent with the results from the study of school readiness to manage food allergies by Rhim and McMorris (2001), principals in 83 % of the schools in this province reported that any teacher in the school would be expected to respond to an acute allergic reaction / anaphylaxis and to administer the emergency medications. The student would then be transferred to the nearest medical facility either by car or ambulance,

depending upon the availability of an ambulance at the time of the emergency. This was of particular concern in rural areas where principals may have to travel long distances to access medical assistance and ambulances may not be readily available. In this study, however, the average length of time to travel from most schools to a medical facility was less than six minutes.

Staff Education on Allergy Management

Annual staff education about life-threatening food allergies, and the monitoring and treatment of an anaphylactic reaction is an integral part of any comprehensive food allergy management strategy (Anaphylaxis Canada, 2005). The majority of schools in this study reported that the school nurse provided annual staff education on food allergies to the *regular* teaching staff, which included the signs and symptoms of anaphylaxis, the triggers of an allergic reaction, and the administration of the EpiPen®.

The two topics that were least often taught were the strategies to prevent an allergic reaction and descriptions of previous allergic reactions in students in the school with known food allergies. These omissions in allergy management education are significant given that the empirical literature suggests that prevention is the key to allergy management in schools (Nowak-Wegrzyn et al., 2001), and that parents are the primary source of food allergy information (Rhim & McMorris, 2001). Parents in this study reported that they were rarely invited to attend or contribute to staff in-service sessions, nor were they informed by the nurse about the content covered in the session or the staff response to the child's allergy. Parents who were kept informed about the allergy management strategies ongoing in a school, reported a greater sense of control over the school environment, which subsequently reduced their overall level of stress.

While regular teaching staff were offered education and training on food allergy management, several errors of omission in educating the school community were identified in this study. Substitute teachers, office and custodial staff, student assistants, and school volunteers were usually not included in the annual staff in-service for a variety of reasons. Schools also lacked reliable alternative mechanisms for informing these personnel about students and their allergies, except through posters placed in the school and substitute teacher notes made available by the regular teaching staff. The lack of preparedness among school bus drivers was identified by both principals and parents as particularly problematic, especially in rural areas of the province where children travelled long distances on a school bus. Principals, while they supported the education and training of bus drivers to recognize and respond to allergic reactions, claimed not to have the authority to enforce mandatory education, and suggested that school boards must establish policies on this issue.

Effective emergency management of anaphylaxis presumes that the individual responding knows when and how to administer the EpiPen® (Gold & Sainsbury, 2000). In fact, studies suggest that one of the factors that contributes to fatal and near-fatal anaphylaxis is a lack of awareness and education about allergy management in schools (Bock et al., 2001; Salter et al., 2001; Sampson et al., 1992). If members of the school community, who are charged with the responsibility of supervising students with food allergies, are omitted from the education session on food allergies, then they will not know how to recognize the signs and symptoms of anaphylaxis or how to respond in an emergency.

Prevention of Allergic Reactions in School

Ontario's proposed Bill 3 emphasizes the importance of developing prevention strategies to reduce the risk of exposure to known allergens (Anaphylaxis Canada, 2005). A comparison of the perceptions held by principals and parents in this study about the level of allergy-awareness among schools attended by students with food allergies provided interesting results.

Over 80 % of principals in this study reported participating in several key allergy-awareness activities. They (a) asked all students and teachers in the school to refrain from bringing food allergens to school, especially in primary/elementary grade levels; (b) asked students to refrain from bringing food allergens on the bus; (c) asked all parents not to send food allergens to the school for parties and celebrations; (d) prohibited the sale of known food allergens in the school; and (e) periodically throughout the year, sent reminder newsletters about allergies to all members of the school community. These activities were more likely to occur in primary/elementary schools than in junior high/high schools. Principals from schools that enrolled teenaged students placed a lot more responsibility on the student to develop the life skills to manage their own allergy.

Over 80 % of parents concurred that schools had attempted to ban food allergens, yet some parents of children with food allergies had been overtly reprimanded by other parents for the food restrictions that had been placed on the entire school community; others recounted stories of teachers who continued to eat food allergens in schools. In contrast to the 80 % of principals, only 68 % of parents reported that the school sent home information in newsletters to remind parents and students about the food allergies in the school, and only 50 % of the parents reported receiving advance notice about

planned events involving food. The incongruence in perceptions held by principals and parents raises interesting questions about the extent to which the allergy-awareness activities were actually enforced in the school setting. Previous similar research on the school management of food allergies (Nowak-Wegrzyn et al., 2001) has not examined the notion of incongruent perceptions between parents and principals; further research in this area may prove fruitful.

Role of the School Nurse

The role of the school nurse is not addressed in the comprehensive strategy for anaphylaxis management proposed in Ontario's Bill 3, but is worthy of discussion here since the school nurse is a health professional whose mandate is to help schools manage health issues. The role of the school nurse in managing students with life-threatening food allergies has diminished, according to principals in this study. Other than providing the annual staff in-service education on allergy management, they did very little to assess the individual needs of students and families with food allergies. Principals stated that nurses were too busy to help schools with allergy management, which is, in part, a result of the recent restructuring of both the health and education systems in this province.

Parents reiterated this finding and many remarked that the nurse seemed non-existent in the school environment, made no attempts to find out the individual needs of their child, and did not communicate with the families about the allergy management activities ongoing in the school. School nurses in this province are often assigned more than one school and may spend as little as one day a week in some schools (personal communication, 2005). In contrast, some schools in the United States employ nurses on site and they have a primary role in food allergy management and emergency response to

allergic reactions (Nowak-Wegrzyn et al., 2001). While Newfoundland and Labrador schools must function within the fiscal realities of the province, the lack of support and communication between school nurses, principals, and parents may be contributing to the deficiencies seen in allergy management and the overall stress levels for all involved. A possible first step towards improving communication between parents, school staff, and the school nurse would be to involve parents in the annual staff education session on food allergies so that they can have the opportunity to provide specific input about their own child's food allergy and be kept informed about allergy management strategies in school.

Deficiencies in Allergy Management Behaviours

Overall, the majority of schools in this study demonstrated positive allergy management behaviours, though there was potential for improvement in virtually every school studied.

A closer analysis of the allergy management behaviours reported by the principals in the study revealed that most of the deficiencies noted in allergy management were clustered within 10 specific schools, one-quarter of the study sample. Most of these schools were junior high or high schools which raises concerns about the relative safety of this age group who, as adolescents, may be more likely to take risks with their food allergy.

Each of these 10 schools was deficient in a number of areas that are inherent in promoting an allergy-aware environment. Only two of these schools were equipped to provide all three essential elements for anaphylaxis management described earlier, namely, an action plan, emergency medications, and a teacher who was able to administer the medication (Boros et al., 2000); the remaining schools were deficient in at least one

of these three areas. In fact, when compared with Ontario's proposed Bill 3 (Anaphylaxis Canada, 2005), all 10 schools in this cluster failed to attain several of the requirements for maintaining an anaphylactic policy. The deficiencies included: (a) the absence of clear policies on food allergy management, (b) inadequate mechanisms for identifying students with food allergies, (c) the absence of action plans or protocols for managing students with food allergies, (d) inconsistent staff education on food allergies, (e) failing to participate in activities to create an allergy aware environment, and (f) unclear and inconsistent emergency response guidelines. Similar allergy management deficiencies have been noted in previous research on allergy management in schools throughout the world (Boros et al., 2000; Rhim & McMorris, 2001; Watura, 2002).

The impact of schools that are deficient in their allergy management behaviours can be seen when examining the in-school allergic reactions reported by principals and parents in four of the schools in this study. Factors in the school environment may have contributed to the occurrence of these food allergic reactions. For example, two of the four schools were part of the cluster of 10 schools that, admittedly, did not participate in activities to create an allergy-aware environment, further supporting the importance of prevention in allergy management.

Schools with large numbers of students with multiple food allergies may have had an added complexity that made it difficult to prevent allergic reactions, as this was the case in the two other schools reporting in-school allergic reactions. Other schools in the sample, however, with large student enrolments and multiple students with food allergies reported no food allergic reactions. Closer examination of these successful schools revealed that they participated in most of the recommended allergy-awareness activities.

The risk of accidental allergic reactions amongst students with life-threatening food allergies was highest in schools that were not proactive in promoting an allergy-aware environment. Junior high and high school students may be particularly at risk since the results of this study demonstrated that, in at least five important areas, these schools carried out significantly fewer allergy-awareness activities than primary and elementary schools (see Table 6). Junior high and high schools made less efforts to eliminate known food allergens from the school environment, and to communicate information about the allergies both within and outside the school. Many principals of teenaged students reported that they expected these students to be self-sufficient in managing their food allergies. While it may be appropriate developmentally to expect teens to accept more responsibility over the management of their food allergies, unanticipated exposures to the food allergen within the school environment due to inadequate restrictions and communication on behalf of the school may place teens at an unfair risk for experiencing a life-threatening allergic reaction in school.

Parents' Perceptions of Schools

Parents' perceptions of how well their child's school accommodated his/her food allergy were generally positive. Three quarters of the parents interviewed rated the school as either excellent or very good in this respect. It is worth noting, however, that none of the 10 schools that had several deficiencies in their allergy-awareness activities were represented by the parent sample. There are several possible explanations for this finding. It is possible that parents from these particular schools were not informed about the study, perhaps related to poor parent-school communication that would be consistent with other deficiencies noted in the schools. Alternatively, the parents from these 10 schools

may have been poorly informed about food allergies, thus explaining why they had not placed demands upon the school for improved allergy management, and why they dismissed the opportunity to participate in this study. Most of the schools with multiple deficiencies in food allergy management were junior high or high schools, and the parents of children in their teens may have chosen to reduce their personal involvement in their child's food allergy management.

One-quarter of the mothers who chose to attend the focus groups reported having several negative experiences in schools related to poor allergy management behaviours. The results of this study support the notion that the behaviours of principals in particular, and school staff in general, have a significant impact on parents' perceptions of allergy management in schools. Principals who maintained open lines of communication, listened to parents, and involved them in allergy management created in parents a sense of control over the school environment. As well, principals who had the authority to make decisions and, more importantly, enforced their decisions to create an allergy-aware environment instilled confidence in parents.

The allergy management behaviours of principals that were viewed as creating negative experiences for families of children with food allergies included failing to restrict food allergens in the school, failing to supervise food restrictions, responding reactively to problems as they arose instead of proactively preventing them, not listening to parents, and not taking the food allergy seriously. Certain behaviours of teachers were identified as problematic, such as being unwilling to listen to parents and learn about food allergies, not knowing where the EpiPens® were located, eating known food allergens in the school, and distributing foods that may contain known food allergens to

other students. There is no other known research that specifically examined the parent's perception of the allergy management behaviour of school staff. Consequently, the results of this study provide valuable insight into the issues that must be addressed if school environment for students with life-threatening food allergies is to be improved.

Sources of Stress for Schools Managing Food Allergies

This study is the first of its kind to begin to explore the sources of stress for school staff who are managing students with life-threatening food allergies. Three primary sources of stress were experienced by the principals in this study, and they are discussed in detail below.

Balancing Individual Rights

The principals in this study reportedly felt stress associated with their responsibility to keep children with life-threatening food allergies safe. At the same time, they empathised with the majority of the non-allergic school community who had to adjust to the food restrictions that were imposed upon them due to the health needs of one per cent of the school population. Virtually every principal encountered this dilemma, though some took a stronger stand than others in their support of one or the other sides of this debate. Some principals, in particular, expressed scepticism about the necessity of the imposed food restrictions and questioned whether parents were as vigilant outside of the school environment. Other principals asserted that improved public education about food allergies was needed in order to help the non-allergic community understand the seriousness of food allergies and accept the approach to allergy management taken by schools.

Questions about the rights of individuals and groups fall within the domain of ethical decision-making, and are not easily answered. This is further complicated in situations where the stakes are high, as in life-threatening anaphylaxis, but the evidence that banning food allergens from the environment actually works is unclear (Hu, Kemp, & Kerridge, 2004). There is no empirical evidence to state conclusively that banning food allergens or participating in any one of the allergy-awareness activities, for that matter, is the key to preventing food-induced anaphylaxis. One principal warned that there is a limit to the restrictions one can place on the rights of the majority non-allergic school community which reflects societal views of the relative costs and benefits of minimizing the risks of food-induced anaphylaxis in schools. This dilemma, given the potentially grave consequences of an anaphylactic reaction in a student, placed principals in this study under a level of stress that should not be underestimated and warrants further investigation.

Feelings of Uncertainty

When the principals in this study elaborated on the issues that caused stress, they alluded to feelings of uncertainty about their own ability to prevent and manage allergic reactions, and the associated legal ramifications. Improved education and preparation at all levels of decision-making regarding food allergies, including clear specific guidelines from the School Board and the Department of Education might be useful in addressing the problems identified in this study.

Increased Workload

The third main source of stress reported by principals in this study was the increased workload associated with managing, not only students with life-threatening

food allergies, but multiple students with a variety of health problems in schools, all while delivering the school curriculum. Watura (2002) in his study of schools in the United Kingdom stated that managing food allergies is just one of the many problems that schools have to deal with. He went on to say that the priority that each school places on the condition may vary, which helps to explain the wide variation in approaches to food allergy management in this province.

Allergy Management Behaviours of Parents, Teens, and Children

While several studies of food-induced allergic reactions in children have described the circumstances associated with the occurrence or recurrence of an allergic reaction (Cianferoni et al., 2004; Kemp et al., 1995; Mullins, 2003), and other research has identified the behaviours that contribute to fatal and near-fatal consequences (Bock et al., 2001; Pumphrey, 2000; Salter et al., 2001; Sampson et al., 1992; Yunginger et al., 1988), there is very little research that documents the day-to day allergy management behaviours of families living with food allergies. This study built upon the previous qualitative study by Mandell et al. (2002) of the information and support needs of families coping with a diagnosis of food allergy in a child. In the previous study, Mandell et al. documented the experiences of families living with anaphylaxis. This study further describes the day-to-day allergy management behaviours, including risk-taking behaviours of families living with life-threatening food allergies. It is only by understanding the decisions and behaviours of parents and children living with this condition that researchers and health care providers can intervene to offer guidance that will reduce the risk of anaphylaxis and improve the quality of life for these families.

The allergy management behaviours of parents, teens, and children with life-threatening food allergies can be discussed under four broad categories including the level of preparedness to manage food allergies, preventative behaviours, emergency response behaviours, and risk-taking behaviours.

Level of Preparedness to Manage Food Allergies

One of the most significant findings of this study was that most parents of children with life-threatening food allergies felt inadequately prepared by health professionals to safely manage their child's food allergy, both at the time of diagnosis and even after years of living with this condition. This finding is consistent with the findings from Mandell et al. (2002) that insufficient information is given to parents at the time of diagnosis of a food allergy.

The part of allergy management that was reported most frequently as misunderstood by parents in this study was the administration of the EpiPen®. They were uncertain about two things: *when* to give the EpiPen® and *how* to correctly administer the EpiPen®. There are several other empirical studies that report similar findings amongst families living with life-threatening allergies (Huang, 1998; Blyth & Sundrum, 2002; Gold and Sainsbury, 2000; Sicherer et al., 2000). Parents in this study were often taught how to administer an EpiPen® by their physician who, like the physicians in the study by Gold and Sainsbury (2000), sometimes used a combination of verbal and written instructions. Only one-half of the parents had had access to a demonstration EpiPen® trainer, either from their physician or from a nurse who specialized in allergy education in a paediatric setting. The lack of demonstration of the EpiPen® was similar to that reported by Huang (1998), in which patients and parents also made errors in the proper

administration of the auto-injector that could have resulted in grave consequences. The inadequate preparation of parents in this study may also be linked to a previously documented lack of preparedness to correctly demonstrate the use of the EpiPen® amongst physicians and other health professionals (Gold & Sainsbury; Grouhi et al., 1999).

Parents in this study who felt adequately prepared to manage their child's food allergy had received comprehensive education from a team of health professionals including a physician, a nurse who specialized in allergy education, and a dietician who taught them how to read labels and avoid food allergens. This finding supports the results from a prospective study of the impact of a comprehensive education program on parental knowledge of allergen avoidance, their management of allergic reactions, and EpiPen® usage (Kapoor et al., 2004). The results of that study demonstrated that parents who received comprehensive education from an allergy specialist, clinical nurse specialist, and a dietician showed significant improvement in their knowledge level, and more importantly, a significant reduction in the rate of allergic reactions one year later.

Parents' responses to their perceived lack of understanding of food allergies was to seek out information from other sources such as parent support groups and the Internet until they felt somewhat prepared to protect their children. Another response was to place strict restrictions on the activities of their children outside the home. Compared to siblings and friends of the same age, the children in this study lived a more sheltered life and did not enjoy the same freedoms as other children. While this was a natural response to the perceived risks associated with many activities, previous research suggests that

high levels of protectiveness must be balanced against debilitating anxiety that can have an impact on the social development of the child (Mandell et al., 2002).

Preventative Behaviours

In an effort to gain control over their child's allergy, mothers in this study reported that they educated their children at a young age to be assertive and to exercise extreme vigilance in all matters involving food. By age 10, most children with food allergies and their close friends and family had been trained in EpiPen® administration by parents in this study. One important allergen prevention strategy that was omitted from the allergy education of children was learning how to inquire about food preparation methods in cafeterias and restaurants. This is a significant omission since while most children in this study ate foods from home when attending school, some children, especially teens, ate out in restaurants and were at risk for eating foods that were cross-contaminated with known food allergens. The education of the child with the food allergy, their friends, and extended family is a recommended approach to the long-term management of life-threatening food allergies (Munoz-Furlong, 2003; Sampson, 2000).

In response to the perceived inadequacies of the school system to keep their children with food allergies safe mothers, like those in the study of families by Mandell et al. (2002), partook in a number of education and prevention activities to protect their children. For example, they ensured that the school principal was aware of their child's identity and the specific food allergy, and that the school had an action plan/protocol to follow to prevent and treat an allergic reaction. They taught their children to carry an EpiPen® at all times while in school. Especially in primary/ elementary grades, the mother of children with food allergies frequently attended field trips outside of the school

and provided foods for parties and celebrations in the school. In general, they spent much of their time monitoring the school environment and looking for potential risks to their children. The majority of mothers who described these activities had children in primary/elementary grades; the involvement of parents with teens seemed to wane as their child reached junior high and high school. This tendency to assign greater responsibility for allergy management to adolescent children, and to place less emphasis upon the behaviours of others, such as school staff, was consistent with similar findings in the study by Mandell et al. (2002). Nevertheless, the prevention strategies employed by parents in this study exceeded the approaches by parents reported in previous research where many failed even to provide the school with epinephrine or to ensure that the staff received EpiPen® training and an emergency action plan (Gold & Sainsbury, 2000; Nowak-Wegrzyn et al., 2001; Rhim & McMorris, 2001; Sicherer et al., 2000).

Emergency Response Behaviors

The cornerstone of the emergency response to an acute allergic reaction/anaphylaxis is an immediate injection of epinephrine, followed by transport to the nearest medical facility for further treatment (Sampson, 2003; Simons, 2004; Simons et al., 2001). One of the biggest concerns arising out of the findings of this study is that, while most parents interviewed owned at least one EpiPen® for their child, they were unsure and hesitant about using it in an acute allergic reaction. When asked during the telephone interview if they felt able to respond to an emergency, 80 % of parents claimed that they would administer the EpiPen®; these responses were inconsistent with the feelings of uncertainty and inadequate preparation expressed by the same parents later during the focus groups when they were given the opportunity to explore their feelings in depth.

In only 2 of the more than 30 allergic reactions in children described by their parents, the parent administered the EpiPen®. Parents opted not to administer the EpiPen® for several reasons. In some cases, they determined that the reaction was mild and chose, instead, to give the child an antihistamine. Others realized in hindsight that the reaction was a serious one, but their inability to recognize the seriousness of the symptoms at the time of the reaction combined with their apprehension about administering the EpiPen® led them to choose to drive their child to the hospital, with an EpiPen® in hand. This is supported by the literature. When Sampson et al. (1992) compared fatal and near-fatal anaphylactic reactions, he found that the presence of parents did not make a significant difference because some parents did not appreciate the potential severity of the allergic reaction, and delayed administering the EpiPen®.

There is considerable variation in the clinical symptoms exhibited by individuals experiencing anaphylaxis, both within individuals having recurrent reactions and between individuals who are allergic to the same food allergens (Sampson, 2003). This known fact about anaphylaxis was reinforced by the mothers in the focus groups who blamed the unpredictability of allergic reactions for their lack of understanding of when to administer the EpiPen®.

The results of this study support what is already known about the knowledge deficiencies amongst individuals and families with food allergies, that is, (a) they did not know how to recognize the symptoms of anaphylaxis and were uncertain about *when* to administer the EpiPen® (Blyth & Sundrum, 2002; Gold & Sainsbury, 2000), and (b) they were not sure *how* to administer the EpiPen® (Huang, 1998; Blyth & Sundrum; Gold & Sainsbury; Sicherer et al., 2000). There is strong empirical support that delays in

administering epinephrine are associated with an increased incidence of biphasic reactions (Fogg & Pawlowski, 2003; Lee & Greenes, 2000) and can contribute to fatal outcomes (Pumphrey, 2000; Sampson, 2003; Simons, 2004). Therefore, the approach by parents in this study may have placed their children at risk for grave consequences and strongly supports the fact that families of children with life-threatening food allergies need to be better prepared by health professionals to recognize the signs and symptoms of allergic reactions and to develop confidence in their ability to administer the EpiPen® when required (Mandell et al., 2002). The importance of parents having confidence in their ability to respond correctly in an anaphylactic emergency has been reported in a recent study of parental use of the EpiPen® for children with food allergies in which the use of the life-saving device was linked more to feelings of empowerment and comfort with the EpiPen®, and less to the knowledge levels amongst parents (Kim, Sinacore, & Pongracic, 2005). This area of investigation warrants further exploration.

Risk-taking Behaviours

Two main factors arose from the findings of this study as precipitating most of the risk-taking behaviours of children, teens and parents living with life-threatening food allergies: human error and the development of a complacent attitude towards the food allergy over time.

Three-quarters of the parents interviewed reportedly had their EpiPen® available for their child virtually 100 % of the time. There were, however, times when the EpiPen® was forgotten. Aside from this common human error which has been reported in earlier research (Kemp et al., 1995), other parents and teens made conscious decisions to leave the EpiPen® at home because either the teen refused to carry it with them, the child/teen was not intending to eat any food, or they felt that the food allergen was easy to identify

so it would be equally easy to avoid. Some mothers also admitted to allowing their children to eat foods, particularly ice cream, that had precautionary labelling or insufficient labelling, especially if they had eaten it in the past without consequence, a behaviour that has been known to contribute to fatal and near-fatal anaphylaxis (Pumphrey, 2000; Sampson, et al., 1992). The results of this study suggest that even amongst a group of conscientious, well-informed parents and teens, risk-taking behaviours formed a part of their life with a food allergy.

One factor that was identified by several mothers and teens as influencing their risk-taking decision-making was the length of time since the last allergic reaction. The longer the child went without experiencing a reaction, the more complacent parents and teens became about carrying the EpiPen® and avoiding the known allergens. This finding supports earlier studies of recurrence of anaphylaxis in which the likelihood of patients carrying epinephrine was inversely proportional to the time since they were originally assessed for anaphylaxis (Mullins, 2003). Patients in the earlier study reportedly “felt safe” since they had not had a reaction for a long time. Mandell et al. (2002) also found that, based on parents’ perceptions, children’s emotional reactions to living with anaphylaxis was diminished by the length of time since the last allergic reaction.

Some of the risks encountered by families living with life-threatening food allergies were unavoidable realities of day-to-day living. Parents in this study acknowledged that every-day activities such as going to parties, eating in restaurants, and travelling all had their associated risks. In general, families limited the frequency and variation in eating out experiences as there was a perceived lack of education and empathy amongst restaurant owners and staff about managing patrons with serious food

allergies; this is a known risk factor for fatal and near-fatal anaphylaxis (Bock et al., 2001; Pumphrey, 2000; Salter et al., 2001; Sampson et al., 1992; Yunginger et al., 1988). Once parents found a restaurant that was well informed about food allergies, they tended to return there for most of their dining out experiences. This is a familiar pattern amongst children with food allergies who find that eating in familiar restaurants reduces their anxiety, though it is socially restricting (Avery et al., 2003; Mandell et al., 2002).

Sources of Stress for Families Living with Food Allergies

It has been well established that those living with life-threatening food allergies experience increased stress (Avery et al., 2003; Gowland, 2001; Mandell et al., 2002; Primeau et al., 2000; Sicherer, Noone, & Munoz-Furlong, 2001), and this study adds to the body of knowledge on the sources of stress by systematically documenting the day-to-day experiences of families, particularly in the school setting. The results of this study suggest that there were multiple sources of stress that can be categorized as: (a) a lack of control over the allergy, (b) a lack of public understanding, (c) a lack of support, and (d) a lack of reprieve from the stress of living with food allergies.

Lack of Control over the Allergy

Parents in this study when told that their child had been diagnosed with a life-threatening food allergy responded with feelings of shock and guilt. Despite the fact that there is no evidence to support this (Sampson, 1996, 2002), many mothers blamed themselves for their child's food allergy because, during the pregnancy, they had consumed large amounts of the food allergen to which their child later became allergic. These intense initial emotions, combined with inadequate preparation from health professionals to manage the allergy, created stress at the time of diagnosis. The findings

from this study confirmed the psychosocial needs of parents reported in a qualitative study by Mandell et al. (2002) which found that insufficient information at the time of diagnosis was a source of stress for families living with food allergies.

Mothers in this study had lived with their child's food allergy for an average of six years and yet, at the time of the study, there still existed persistent misunderstandings about the food allergy and the proper use of the EpiPen®. The mothers' lack of confidence in their abilities to prevent and treat an allergic reaction, combined with the perceived unpredictability of allergic responses, left them feeling a lack of control over the illness, resulting in considerable burden and stress.

Parents in previous research tried to reduce their stress by achieving mastery over the condition and the dietary restrictions (Primeau et al., 2002). While the parents in this study attempted to gain control over the perceived risks associated with the food allergy by placing limits on the activities of their children, they also felt guilty about the injustice of their children's restricted lifestyle. While this study did not attempt to measure the parents' perception of their children's quality of life, the pervasive feelings expressed by parents were supportive of the results from previous research by Sicherer, Noone, & Munoz-Furlong (2001) that children with food allergies experience a lower health-related quality of life. The parents in this study reported that their children spent much of their childhood worrying about all matters involving food, reading labels, and assessing their environment, and, because of the unavoidable restrictions associated with living with a life-threatening food allergy, their children suffered from isolation and exclusion in many social situations. Gowland (2001) reported that social isolation was part of the reality of living with food allergies. When teens were questioned about this aspect of living with a

food allergy, however, many of them downplayed this issue and expressed acceptance of their restricted lifestyle stating, "It's just the way I grew up."

Parents' feelings of control over the allergy were also influenced by their child's stage of growth and development. Developmental issues have been previously indicated as significant contributors to parental anxieties and fears (Mandell et al., 2002). Parents of very young children in this study worried about their children's abilities to protect themselves in all situations involving food. Routine activities such as attending school, visiting a friend, or going to a party were fraught with anxiety and stress. They struggled with "letting go" of their children and trusting them to someone else's care. The beginning of the school year was identified as a time of particularly high stress as parents were forced to relinquish control over the allergy management to school staff who were perceived to have varying levels of preparedness to handle the responsibility, a concern which is supported by previous research (Mandell et al.; Primeau et al., 2000). Parents in this study also worried about the future handover of control of the allergy to the teenaged child.

Mothers of teens expressed anxiety about their current lack of control over their child's activities including issues of dating, eating out, remembering to carry the EpiPen®, and knowing how to use it in an emergency. They, too, worried about the future when their children would begin to live independently, and wondered whether their restricted childhood would have an impact on their ability to function independently in society as an adult.

The greatest sources of stress associated with a food allergy identified by parents in this study were their loss of control over their ability to keep their child safe and the perceived loss of freedom experienced by their children.

Lack of Public Understanding

Parents identified the lack of public understanding and empathy for this life-threatening condition as one of the most important obstacles that needed to be overcome in order to improve the lives of their children. This has been identified in previous research (Mandell et al., 2002), and was particularly evident in this study where some parents of non-allergic students clearly did not understand the seriousness of food allergies and resisted, both covertly and overtly, the school-imposed food restrictions. Similarly, a lack of understanding of food allergies amongst individuals working in the travel, food manufacturing, and restaurant industries significantly added to the stress experienced by families living with life-threatening food allergies who wished, as others do, to eat out in restaurants or take a vacation. Parents thought that one solution to this problem would be to improve public education and awareness about food allergies, even though there have been considerable efforts in that regard already (Anaphylaxis Canada, 2005; Munoz-Furlong, 2003).

In particular, the teens who participated in this study were stressed by a pervasive tendency among uninformed people to try to coerce them to eat foods that others had prepared and believed to be safe – even if the food was possibly cross-contaminated by a known allergen. Parents, like those in the study by Mandell et al. (2002), responded to this by teaching their children from a young age to be assertive, to question adults about foods, and to make the final decision about food consumption based on their own

assessment of the food. All things considered, this placed a significant responsibility on the child or teen with the food allergy, and it is not surprising that it was identified as a source of stress by teens in the study. While this study did not purport to analyze the perceived quality of life for children and teens with food allergies, the results are consistent with the poor quality of life reported by children with peanut allergy related, primarily, to anxieties of having an allergic reaction and threats of potential hazards in the environment (Avery et al., 2003).

Lack of Support

Consistent with the results from a qualitative study of the psychosocial needs of families living with anaphylaxis (Mandell et al., 2002), the responsibility for managing the child's food allergies in this study fell primarily upon the mother. Mothers in the focus groups felt the greatest burden of responsibility to make accommodations for the child's food allergy, practice vigilance in all matters involving food, and defend the rights of the child in a variety of situations, whether at school or in the homes of friends and relatives. The stress associated with keeping their children with allergies safe should not be underestimated.

The presence of a child with a life-threatening food allergy may have an impact on other family members. Though infrequently mentioned, some mothers reported that siblings of the child with the allergy felt ignored because so much of the mother's time and energy was directed towards keeping the child with the allergy safe. While some mothers reported that their extended families were supportive, others had experienced conflict because the relatives had not taken the allergy seriously and in the view of the mother had placed the child at risk of an allergic reaction. Some mothers also asserted that their husbands were not vigilant about reading labels and could not be relied on to

respond in an emergency, causing stress for the mother. The stress created in the home by fathers who are less vigilant about managing the child's food allergy is supported by an earlier study by Mandell et al. (2002) who recommended including both parents in a family-based approach to educating families and developing coping strategies.

Another source of stress identified by parents in this study was the lack of support from food manufacturers who added known allergens to foods and placed precautionary labels on food packages, primarily for the protection of the company from legal liability. Precautionary labelling interferes with the individual's ability to make informed decisions about the real allergen risk (Gowland, 2001). Ice cream, in particular, was singled out as the most important food unavailable to children in this province with allergies to nuts and peanuts.

The lack of provincial school policies and standards for the safe management of students with life-threatening food allergies, were identified by parents as major obstacles to improving the lives of those afflicted with this condition. Parents in this study were forced to negotiate with teachers and school administrators every year, and this was taking its toll on parents. The experiences of parents in this study are consistent with those described by Laurie Harada, Executive Director of Anaphylaxis Canada, in response to the tragic death of an Ontario teen who experienced an anaphylactic reaction in school (Canada NewsWire, 2003). While keeping a child with a life-threatening food allergy safe is a responsibility that is shared by the child, the family, and the school, whether or not a school has a good allergy management policy in place depends on the level of the principal's commitment and the ability of parents to communicate their needs to schools. The results of this study lend support for Ontario's Bill 3, which requires that

every school board establish and maintain an anaphylactic policy (Anaphylaxis Canada, 2005), and will help to eliminate the inconsistencies in allergy management such as those found in schools that were a part of this study. Similar forms of legislation in other provinces of Canada, including Newfoundland and Labrador, may help to address some of the problems identified in this study. At the very least, the results of this study support the need to adopt the underlying principles of Bill 3 to individual school board policies on anaphylaxis in this province.

Lack of Reprieve from Stress

The possibility that their child could die from food-induced anaphylaxis was a fear that parents in this study faced daily and was identified as one of their greatest sources of stress. This fear is supported by an earlier study which found that parents living with children with a peanut allergy experienced a greater psychological burden than parents of children with rheumatological disease, due, in part, to their perceptions of the child's risk of death (Primeau et al., 2000).

Fears for the safety and well-being of the child never completely went away and were intensified whenever there was a change in routine. Many parents, reportedly found the beginning of every school year to be very stressful, especially if their child was moving into a new school. Mandell et al. (2002) also described oscillating patterns of anxiety levels whereby key events such as a new incident of an accidental exposure to an allergen, the discovery of previously unknown risks, or developmental changes which exposed the child to increased risk triggered an intensification of anxiety.

Few benefits were identified by mothers and teens as a consequence of living with a food allergy, though children were seen by their parents as being more compassionate and assertive than other children in the same age group.

CHAPTER VI

Limitations and Implications

This chapter presents a discussion of the limitations and implications of the study findings. The study has limitations related to the sample, response bias, and the measurement tools used to collect data. The implications of the study for schools, health care, and future research are presented.

Limitations of the Study

The Sample

While the school sample was randomly selected from a complete list of English-speaking, public schools in the province, the study design excluded private and special schools, French-speaking schools, and small schools with enrolments of less than 100 students. Primary/elementary schools were represented slightly more than junior high/high schools, but the distribution of grade levels in the study was comparable to the provincial distribution. The final sample was representative of most provincial schools and the study findings can only be generalized to schools in the province that meet the same criteria of those included in the study sample.

It is not known how many schools in the province actually had students with life-threatening food allergies in attendance. Hence the 75 % of affected schools in this study with a prevalence of food allergies among students of close to 1 % may not be truly representative of the magnitude of the problem in this province. Since many schools in the study lacked established policies for identifying and managing students with food allergies, there were likely students with allergies who were not known to the principal. Accordingly, the results of this study may underestimate the true prevalence of food

allergies amongst school-aged children in the province. A future study should also collect data on the gender of all students with food allergies so as to add to the body of knowledge on the prevalence of food allergies among males and females. It may be that allergies to specific foods may be more prevalent amongst one gender over another.

Response Bias

Four principals who met the study criteria did not participate in the study, stating that they were too busy to be interviewed. School principals who responded to the study may have been better informed about food allergies and may have placed a higher priority on this issue than those who refused to participate. In addition, social desirability bias may have resulted in findings that were consistent with prevailing social mores, yet presented a more favourable image of allergy awareness than actually existed in schools.

The response rate amongst parents was lower than that for principals, with just 33 % parental participation. The reasons for this are unknown but may have been related to how carefully the principals in the participating schools ensured that the invitation to participate was actually received by the parents of students with life-threatening food allergies. For example, three schools with multiple deficiencies in allergy management came from the school districts selected for the parent survey but none of the parents from these three schools contacted the investigator to participate in the study. Furthermore, the guidelines for ethics approval of this study prohibited the investigator from obtaining the names of the students with food allergies from the principal, thus eliminating the option of direct invitation or follow-up with the family, an approach which otherwise may have improved the response rate amongst parents.

The views of parents who self-selected to be interviewed and to participate in the focus groups may differ from those who received the invitation but chose not to participate. The participants were primarily mothers of children in primary-elementary school. The fact that mothers participated, and not fathers, is somewhat expected in survey research, but also supports the finding that the responsibility for the management of the child's food allergy rests primarily with mothers.

Only 5 of the 25 parents in the study had teenaged children with food allergies. The under-representation of this age group was disconcerting for several reasons. Teens may be more likely to take risks associated with their allergy management, may wish to hide their allergy to avoid being viewed as different from their peers, are under less supervision both at home and at school and, according to the principals in this study, are expected to take greater responsibility for allergy management. The fact that so few parents of teens participated in the study is another indicator that teens may be assuming personal responsibility for their allergies; parents who have distanced themselves from the allergy management may have been less likely to participate. Despite the difficulties in recruiting teens for research, a future study that focuses on the needs and behaviours of teens is warranted.

The findings gathered from parents who agreed to participate in this study may differ from those who chose not to respond to the invitation to participate. The parents who participated may have been more worried and cautious about the food allergy or may have felt more knowledgeable than those who did not participate. It is likely that the allergy management behaviours reported by parents in this study represented higher levels of vigilance taken by families living with this life-threatening condition. Future

research on this topic should attempt to gather information from parents who represent the full range of perspectives on food allergy management.

Measurement Tools

The measurement tools (Allergy Profile for Schools and Allergy Profile for Parents) were developed by the investigator specifically for this study. While some of the questions were asked in previous studies, the validity and reliability of the findings of these new instruments cannot be established until they have been subjected to repeated use in a variety of settings.

The approach taken of combining parents and teens in the focus group discussions may have affected the teen's willingness to freely discuss issues related to living with a life-threatening food allergy, but, this was the only practical way to conduct this part of the study.

The limitations of this study parallel those of previous studies. However, given these cautious notes, the findings of this study can be used in policy development and education programs.

Implications of the Study

The results of this study have implications for schools, health care, and for future research on life-threatening food allergies.

Implications for Schools

The findings of this study provide empirical evidence that increasing numbers of students with life-threatening food allergies are being identified in schools in this province, and that the majority of schools in the province are affected by this issue. Food-induced anaphylactic reactions occur in the school setting and schools need to be

prepared to manage students with life-threatening food allergies. One-quarter of the schools in this study reported important deficiencies in their allergy management that may have placed students at risk for anaphylaxis. The responsibility associated with creating an allergy-aware environment creates stress for school staff who must manage the increased workload and balance individual rights. School staff who demonstrate deficiencies in allergy management create stress for the children and their families who are living with life-threatening food allergies.

Deficiencies in the management of life-threatening food allergies in school may be placing students with allergies at an increased risk for anaphylaxis, with potentially grave outcomes. This finding, combined with the increased stress created for children, families, and school staff, points to a need for a comprehensive provincial school policy on food allergy management, preferably one that is passed into legislation similar to Ontario's Bill 3. Some of the essential elements of a provincial strategy found lacking in the current approaches to allergy management include: a) a procedure for identifying students with food allergies; b) a written action plan/protocol for every student with food allergies; c) a mandate that addresses the minimum number and location of required EpiPens® per student; d) activities to promote an allergy-aware school environment; e) clear guidelines regarding the transport of students to medical facilities during an emergency; f) comprehensive allergy management education and involvement of the school principal; g) annual in-service education of all school staff, including substitute teachers, student assistants, and bus drivers on all aspects of allergy management; h) an identification of the most appropriate health professional to assist in allergy management in the school setting, particularly as this relates to individualized assessment of students

and families; i) improved methods of communication with parents to gather input about their child and the allergy, and to inform parents of the allergy management strategies ongoing in the school; and, j) strategies for educating the non-allergic school community about food allergies.

A provincial strategy that provides the necessary resources and addresses each of the essential elements of food allergy management while taking into account the individual needs of students and families is indicated in all schools in the province, including junior high/high schools. One of the recommendations of this study is that the Department of Education hire a qualified individual to monitor and assist all students with food allergies through the duration of their public education experience.

Implications for Health Care

The findings from this study support the notion that there is a gap between the information provided by health professionals to families living with life-threatening food allergies and that which is needed by families to cope with this condition. The education of health professionals, particularly physicians who diagnose and treat individuals with food allergies, should be reviewed from the perspective of the acquisition of the patient education skills necessary to ensure that families under their care are adequately prepared to recognize and treat anaphylaxis.

Based on the results of this study, every family who participated would have benefited from comprehensive education on food allergies from a team of health professionals that included: a) strategies to prevent an allergic reaction, b) instructions on how to read food labels to identify allergens, c) education about the importance of cross-contamination and precautionary labelling, d) guidance about how to inquire about food

preparation in restaurants and cafeterias, e) explanation of the signs and symptoms of anaphylaxis that indicate the need for emergency medications, and, most importantly, f) clear instructions on when and how to administer an EpiPen®. Particular emphasis is needed to prepare teens to safely manage their food allergy and minimize the risk of grave outcomes from anaphylaxis. Parents who have been adequately prepared to manage food allergies can further educate their child with the allergy, extended family members, friends, and the school community.

There is a paucity of empirical evidence about the sources of stress for families living with life-threatening food allergies. Families, especially mothers, bear the burden of this stress and struggle to find the balance between keeping their child safe and avoiding extreme restrictions that may have an impact on the child's psychological and social development. Health care resources should be directed towards teaching families strategies to make the lifestyle adaptations necessary to live with life-threatening food allergies including: a) keeping their child safe while avoiding unnecessary restrictions that could be socially isolating, b) adjusting to the growth and developmental needs of their child, c) making informed decisions about risk-taking behaviours, d) avoiding becoming complacent about the allergy over time, e) discovering appropriate stress reducers, f) drawing upon the strengths of all members of the family to gain control over day-to-day stress of living with a life-threatening food allergy. Support for families may be developed by psychologists, social workers, and/or appropriate food allergy support groups in the community.

Lastly, the results of this study support the need for a public education and awareness campaign to increase understanding about the challenges of living with food

allergies. Improved education may help reduce the incidence of potentially harmful behaviours on the part of the uninformed public such as, coercing children with food allergies to eat unsafe foods, disregarding the food restrictions in a school environment, and cross-contaminating foods in restaurants and cafeterias, to name a few. The lack of public support was identified by families as one of their greatest sources of stress. Strategies on behalf of health professionals to educate the general public may result in a more supportive environment for families living with life-threatening food allergies.

Implications for Future Research

This study was an exploratory descriptive study and the results have provided insight into a number of areas that require further investigation.

A study of the attitudes and behaviours of teens, including risk-taking behaviours, should be explored in greater detail than was possible in this study. This age group may have unique needs that are currently being overlooked by schools and families.

Further research is warranted that focuses on the experiences of fathers of children with life-threatening food allergies, in particular, to examine whether fathers assess the risks associated with food allergies differently than mothers, thus explaining some of the differences found in their allergy management behaviours.

Research into the views held by school nurses, community nutritionists, teachers, guidance counsellors, and the non-allergic school community regarding their respective roles in allergy management in the school environment may provide useful explanations for the possible lack of support from these groups and lead to strategies to enlist their support and understanding of food allergies.

While there is a generally held belief that an allergy-aware school environment protects children with food allergies, research is needed to determine the specific allergy management behaviours that are most effective and efficient in reducing accidental exposures to food allergens, and increasing favourable outcomes from acute allergic reactions.

Research is needed to determine which combinations of "life skills" on the part of the child and "protectiveness" on the part of the parents produce the best overall outcomes for the child with a food allergy, help families to take control of the food allergy, and assist children to move through adolescence and adulthood with the greatest potential for living successfully with a life-threatening food allergy.

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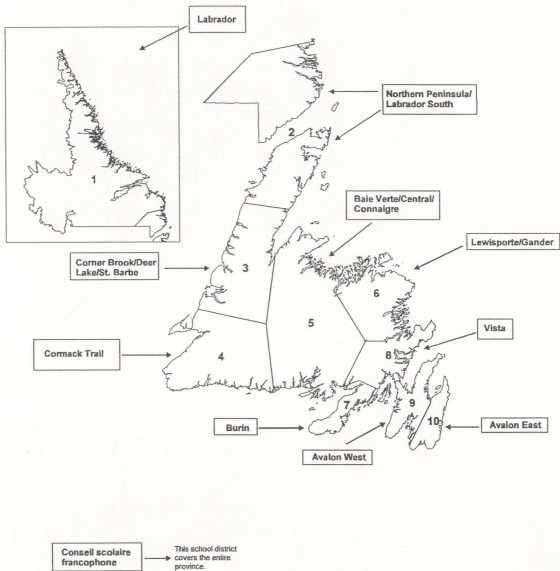
APPENDIX A

Clinical Signs and Symptoms of Anaphylaxis

Oral	Tingling/itching of the lip, tongue and palate; swelling of the lips and tongue; metallic taste in the mouth
Gastrointestinal	Nausea, abdominal pain, vomiting, diarrhea
Skin	Flushing / redness, itching, hives, swelling, rash
Respiratory	<i>Upper</i> Nasal congestion, sneezing, runny nose, hoarseness, itching and 'tightness' in the throat, cough, difficulty swallowing, swelling of the inside of the throat, obstruction of throat, itching in the external ear canal <i>Lower</i> Shortness of breath, difficulty breathing, chest tightness, rapid breathing, deep cough, wheezing, cyanosis, respiratory arrest
Cardiovascular	Feeling of faintness, fainting, rapid / irregular heart beat, chest pain, drop in blood pressure, cardiac arrest
Other	Sense of impending doom, itchiness around the eyes, redness of the conjunctiva of the eye, watery eyes, dizziness, weakness, seizures, lower back pain, uterine contractions in women

APPENDIX B

2000-01 School Districts



APPENDIX C

**Allergy Management Behaviours and Sources of Stress for Schools and Families
Living with Life-threatening Food Allergies**

Allergy Profile for Schools*

Participant Number: _____

I will begin the interview with some general questions about your school.

1. What is your position in this school?
☐ Principal
☐ Vice-principal
☐ Guidance Counsellor
☐ Teacher
☐ School Nurse
☐ Other (please specify) _____

2. How many years have you worked in this school?
 _____ years

3. What grade levels are taught at this school? (check all)
☐ Primary (K-3)
☐ Elementary (4-6)
☐ Junior High (7-9)
☐ High (Levels 1-3)

4. How many students are in your school?
 _____ students

Next I will be asking you some questions about students with food allergies who are currently enrolled in your school.

5. To the best of your knowledge, **how many students** in your school have food allergies severe enough to require epinephrine (e.g. EpiPen®) in the event of a life-threatening allergic reaction?
☐ students
☐ I don't know

*Portions of this instrument have been adapted with permission from questionnaires designed by Anna Nowak-Wegrzyn, M.D. (Nowak-Wegrzyn, Conover-Walker, and Wood, 2001) and Grace S. Rhim, M.D. and Marc S. McMorris, M.D. (Rhim and McMorris, 2001).

6. **Which food(s)** are the students allergic to? Please include the number of students allergic to each food. (Read each food and insert #)

<input type="checkbox"/> Milk	<input type="checkbox"/> Peanuts
<input type="checkbox"/> Egg	<input type="checkbox"/> Tree Nuts(e.g.almonds, cashews, walnuts)
<input type="checkbox"/> Soy	<input type="checkbox"/> Shellfish (e.g. crab, shrimp, lobster)
<input type="checkbox"/> Wheat	<input type="checkbox"/> Fin Fish (e.g. cod, salmon, halibut)
<input type="checkbox"/> Kiwi	<input type="checkbox"/> Other (please specify) _____

7. **Who informed** you about these students with food allergies? (check all)

☐ Parents of student with food allergy
☐ Student with allergy
☐ Student's doctor
☐ School nurse
☐ Teacher
☐ Was not notified – found out by accident
☐ School records passed on from feeder school
☐ Other (please specify) _____

8. Do you have an **action plan/ poster** for each *individual* student that describes the actions to be taken in the event of an allergic reaction (often with a picture of the student attached for easy identification)?

☐ No, there are no posters of students
☐ Yes, on a standard form/poster for the treatment of allergic reactions
☐ Yes, the school provided a form for the parent to complete
☐ Yes, written by parent (i.e. hand-made)
☐ For some students, but not all
☐ Other (please specify) _____

The following questions pertain to your school's general approach to the management of students with food allergies. The questions do not refer to individual students, but rather to the procedures followed in your school when you have students with life-threatening food allergies.

9. Do you have a formal written **policy/protocol** on the management of students with food allergies?

☐ There is no school policy/protocol at all
☐ Yes, it is a district-wide written policy/protocol
☐ Yes, a school-based written policy/protocol
☐ Yes, but it is not formally written –a general understanding
☐ Other (please specify) _____

10. Does your school complete an **Individual Student Support Plan (ISSP)** for students with life-threatening food allergies at the beginning of the school year?

☐ Yes
☐ No

11. Once you are made aware that a student attending your school has a severe food allergy, **who is primarily in charge** of making sure that procedures are carried out to ensure the safe management of that student's allergy? (check all that apply)

☐ Principal
☐ Principal's designate in charge of food allergies (i.e. study participant)
☐ Student's teacher
☐ Parent/ Legal Guardian
☐ School Nurse
☐ Guidance Counsellor
☐ Varies – nobody in particular
☐ Other (please specify) _____

12. Are your staff members **required** to attend inservice on the management of students with food allergies?

☐ Yes, they attend an annual inservice (go to # 13)
☐ Yes, they attend inservice education periodically (go to # 13)
☐ They are not required to attend inservice education (go to #15)
☐ Inservice education is not provided in this school (go to # 15)
☐ Other (please specify) _____

13. **Who is required** to attend inservice education on the management of student's with food allergies? (check all)

☐ All regular teaching staff
☐ Substitute teachers
☐ Office / custodial staff
☐ Bus drivers
☐ Parents of children with food allergies
☐ Other (please specify) _____

14. I will read to you a list of **topics pertaining to food allergies** and will ask you to **identify who**, to the best of your knowledge, has taught this topic to school personnel in the past? Possible people who have taught school personnel:

1 = you (Principal or designate)
 2 = school nurse
 3 = doctor
 4 = parent of child with food allergy
 5 = other
 6 = not taught to your knowledge

Topics pertaining to food allergies:

☐ Signs and symptoms of an allergic reaction/anaphylaxis
☐ Triggers of an allergic reaction
☐ Strategies to prevent an allergic reaction from occurring
☐ Procedures for responding to an allergic reaction
☐ How and when to administer epinephrine (e.g. EpiPen®)
☐ Description of what previous allergic reactions have been like

15. **How many EpiPens®** are parents/guardians of students with life-threatening food allergies **required** to make available to the school to be used in the event of an allergic reaction?
- ☐ No EpiPens® are required
 - ☐ 1 EpiPen® per student
 - ☐ 2 EpiPens® per student
 - ☐ Number of EpiPens® provided varies from student to student
 - ☐ Other (please specify) _____
16. Do students with food allergies **carry their medications** (e.g., EpiPen®) on their person at all times?
- ☐ No (Go to question # 18)
 - ☐ Yes, it is required (Go to question # 17)
 - ☐ Yes, they are permitted but not required (Go to question # 17)
17. At what **grade level** do students with life-threatening food allergies carry epinephrine (e.g., EpiPen®) on their person (i.e. minimum grade level)?
- ☐ Primary (K-3)
 - ☐ Elementary (4-6)
 - ☐ Junior High (7-9)
 - ☐ Senior High (Levels I – III)
 - ☐ Varies depending on the student (e.g., behavioural/cognitive concerns)
 - ☐ Varies depending on parental consent
 - ☐ Don't know
18. **Where** are the medications for allergic reactions kept (i.e. EpiPens®)? (check all that apply)
- ☐ Main office
 - ☐ Health room
 - ☐ Centrally located area, near the students
 - ☐ Teacher's desk (in classroom with allergic student)
 - ☐ Student carries own medications
 - ☐ Student's locker
 - ☐ I don't know
 - ☐ Other (please specify) _____
19. Have you ever been in the situation where parents/guardians of students with life-threatening food allergies **do not provide** the school with emergency medication (e.g., EpiPen®)?
- ☐ Yes
 - ☐ No

20. Many schools that have students with food allergies attempt to minimize the risk of accidental exposure to the foods by imposing **restrictions on the presence of the allergenic foods** in the school environment. Which, if any, of the following restrictions apply to your school environment when you have a student with a severe food allergy? (check all that apply)

- ☐ Request that *all* students in the school refrain from bringing the allergenic food to school
- ☐ Request that *only* students in the same classroom refrain from bringing the allergenic food to school
- ☐ Request that foods that "may contain" the allergen are banned
- ☐ Request that students do not bring the allergenic food on the bus
- ☐ Refrain from selling the allergenic food in the cafeteria or vending machines
- ☐ Provide allergen-free eating areas/tables
- ☐ Request that the allergen not be used in science or heritage fairs, or any other school-related activity
- ☐ Request that all teaching and non-teaching staff not bring known allergens into the school for consumption in the teacher's staff room/ lunch room
- ☐ Inform all school volunteers about the food allergy
- ☐ Inform all substitute teachers about the food allergy
- ☐ Refrain from selling the allergenic food for fund-raising activities
- ☐ Request that all students/parents do not bring the allergenic food to school for celebrations, parties, graduations involving food
- ☐ Send out reminder letters/ newsletters periodically throughout the year
- ☐ Place allergy aware posters and signs around the school
- ☐ Other (please specify) _____
- ☐ There are no food restrictions in this school

21. When a student goes on a school **field trip**, **who** is responsible for ensuring that the emergency medications (e.g. EpiPen®) accompany the student? (check all that apply)

- ☐ Principal or designate
- ☐ Homeroom teacher
- ☐ Subject teacher
- ☐ Teacher in charge of field trip
- ☐ Assigned teacher chaperone
- ☐ Student with allergy
- ☐ Parent of student with allergy
- ☐ Varies from student to student
- ☐ No one is responsible
- ☐ Other (please specify) _____

22. In the event of an acute allergic reaction/anaphylaxis in a student with a known food allergy, **who would be expected to respond and administer** the emergency treatment (e.g. EpiPen®)? (check all that apply)
- ☐ Principal or designate
 - ☐ Student's homeroom teacher
 - ☐ Any teacher present during the reaction
 - ☐ School nurse
 - ☐ Guidance councillor
 - ☐ Emergency response team (group of trained teachers)
 - ☐ Varies from student to student, reaction to reaction
 - ☐ The student with the allergy
 - ☐ No one is expected
 - ☐ Other (please specify) _____
23. If a student has an acute allergic reaction/anaphylaxis at your school, how will that student be **transported to the nearest medical facility**?
- ☐ Call EMS (911) and wait for an ambulance
 - ☐ By car, with teaching staff
 - ☐ Other (please specify) _____
24. Approximately **how long** would it take to travel from the school to the nearest medical facility?
- ☐ _____ minutes
 - ☐ I don't know
25. To the best of your knowledge, has a student ever had an **allergic reactions/anaphylaxis** to foods such that you had to administer epinephrine?
- ☐ No (Go to question # 27)
 - ☐ Yes (Go to question # 26)
 - ☐ I don't know (Go to question # 27)
26. **How many** allergic reactions/anaphylaxis have occurred in your school?
- ☐ _____ acute allergic reactions/anaphylaxis
27. Do you have students with life-threatening food allergies in your school who **travel to and from school on the school bus**?
- ☐ Yes
 - ☐ No
28. To the best of your knowledge, has a student ever had an allergic reaction/anaphylaxis to foods while traveling to and from school on the school bus?
- ☐ Yes
 - ☐ No

29. Do you have any comments to make about the sources of stress associated with the management of students with life-threatening food allergies in schools (e.g., **bullying** of students with allergies, **complaints** from non-allergic community about food restrictions in school)?

Thank you for agreeing to participate in this study. The information gained in this research will assist schools to better meet the needs of students with life-threatening food allergies. At the completion of the research, a copy of the results will be mailed to you.

APPENDIX D

*Allergy Management Behaviours and Sources of Stress for Schools and Families
Living with Life-threatening Food Allergies*

Allergy Profile for Parents*

Participant Number: _____

I will begin the interview with some general questions about the history of your child's food allergy.

1. What is your **relationship** to the child with the food allergy?
 - ____ Mother
 - ____ Father
 - ____ Legal Guardian
 - ____ Other (please specify) _____

2. What is your child's **age**? _____ years

3. Is your child a boy ____ or a girl ____? (check one)

4. Which **food(s)** is your child allergic to? (check all that apply)

____ Milk	____ Peanuts
____ Egg	____ Tree Nuts
____ Soya	____ Shellfish
____ Wheat	____ Fin Fish
____ Kiwi	____ Other _____ (specify)

5. At what age was your child **diagnosed** with a food allergy?
 _____ years

6. So, your child and family have been living with the diagnosis of a food allergy for
 _____ years. (Subtract Answer # 5 from Answer # 2)

7. **How did your doctor diagnose** your child with a food allergy? (check all)
 - ____ On the basis of clinical symptoms (e.g. hives, tight throat, swelling)
 - ____ By skin and/or blood testing by an allergy specialist
 - ____ By skin and/or blood testing by a pediatrician (a doctor who specializes in treating children)
 - ____ Other (please specify) _____

* Portions of this instrument have been adapted with permission from a questionnaire designed by Anna Nowak-Wegrzyn, M.D. (Nowak-Wegrzyn, Conover-Walker, and Wood, 2001).

8. Has your child seen an **allergist** (allergy specialist)?
 ___ Yes
 ___ No
9. Has your child ever been diagnosed by a physician with any of the following **conditions**? (check all)
 ___ Asthma
 ___ Eczema (atopic dermatitis)
 ___ Rhinitis (inflammation of the nasal cavity)
 ___ Environmental allergies (e.g. dust, cats, dogs, pollen)
 ___ Other food allergies (non-life-threatening)
 ___ Other (please specify) _____
10. Has any member of your child's **immediate family** (i.e. parents, siblings) been diagnosed by a physician with any of the following conditions? (check all)
 ___ Asthma
 ___ Eczema (atopic dermatitis)
 ___ Rhinitis (inflammation of the nasal cavity)
 ___ Environmental allergies (e.g. dust, cats, dogs, pollen)
 ___ Food allergies
 ___ Other (please specify) _____

Next, I will be asking you some questions about the acute management of your child's food allergy. Your child has a severe food allergy and has been prescribed epinephrine for the emergency treatment of an allergic reaction. Epinephrine is available in a variety of medication devices.

11. Which **medication device** has been prescribed for your child to be used in the event of an allergic reaction? (indicate # of each device)
 ___ EpiPen®
 ___ AnaKit®
 ___ Ampoules of epinephrine to be drawn up in a needle and syringe
 ___ Other (please specify) _____
12. **How old** was your child when he/she was prescribed epinephrine to be used in the event of an allergic reaction?
 ___ years
13. **Who prescribed** the epinephrine for your child?
 ___ Family doctor
 ___ Allergy specialist
 ___ Pediatrician
 ___ Other (please specify) _____

14. I would like you to think back to when your child was first prescribed emergency medication (i.e., EpiPen®). In what **way(s) did the doctor explain** the proper use of the medication device? (check all)

☐ Verbally explained how to use it
☐ Provided written instructions on how to use it
☐ Demonstrated the use of a device by using a trainer
☐ Referred you to a nurse who demonstrated the correct method
☐ Other (please specify) _____
☐ The doctor did not explain how to use the device

15. Do you feel comfortable that you would **know how to use** an EpiPen®/ AnaKit® in the event of an allergic reaction in your child?

☐ Yes
☐ No
☐ Unsure
☐ Other (please specify) _____

16. Some people feel hesitant when told that they will need to give a needle to their child in the event of an anaphylactic reaction. Do you feel **comfortable with the idea of giving** an EpiPen® to your child in an emergency (i.e., anaphylaxis)?

☐ Yes
☐ No
☐ Unsure
☐ Other (please specify) _____

17. A single EpiPen®/ AnaKit® can be costly to purchase. How do you cover the **cost** of purchasing EpiPens®/ AnaKits®?

☐ Health Insurance Plan
☐ Health Insurance Plan ONLY with special authorization
☐ Government Assistance
☐ Personal out-of-pocket money
☐ Other (please specify) _____

18. Some people living with food allergies purchase more than one EpiPen®/ AnaKit® at a time so that they can permanently keep one device at places where their child spends a lot of time. Where have you **permanently placed** an EpiPen®/ AnaKit® for your child? (check all locations)

☐ Child's home
☐ Child's school
☐ Child's school bag, fanny pack or purse
☐ Babysitter's home/ Daycare
☐ Home of extended family
☐ Homes of child's friends
☐ Mom's purse
☐ Other (please specify) _____

19. Which of the following groups of **people have you taught/explained** the proper use of an EpiPen®/ AnaKit® to? (check all)
- ☐ Child with food allergy
 - ☐ Members of immediate family (spouse, siblings)
 - ☐ Members of extended family
 - ☐ Friends of the allergic child
 - ☐ Parents of the friends of the allergic child
 - ☐ School personnel
 - ☐ Babysitter/ Daycare personnel
 - ☐ Other (please specify) _____
20. You have probably been instructed to ensure that an EpiPen®/ AnaKit® is accessible to your child at **all times**. Sometimes, despite our best efforts, we forget to carry an EpiPen®/ AnaKit®. In general, **what percentage of time** do you remember to ensure that an EpiPen®/ AnaKit® is accessible to your child wherever he/she goes?
- ☐ Less than half the time
 - ☐ Most of the time, but not always
 - ☐ Almost 100% of the time, with few exceptions
 - ☐ Absolutely 100% of the time
 - ☐ I leave it up to my child to remember
21. Which of the following **reasons** can explain why your child would not have an EpiPen®/ AnaKit® with him/her? (Check all reasons)
- ☐ Simply forget
 - ☐ Not intending to eat anything at the time
 - ☐ Feel safe because the allergenic food is easy to identify and avoid
 - ☐ Child does not react to air-borne allergens
 - ☐ It's been a long time since the child had an allergic reaction
 - ☐ All prior allergic reactions were mild
 - ☐ Don't really believe that my child has a food allergy
 - ☐ The medications cost too much money
 - ☐ The medication expired and I was not aware of this
 - ☐ Other (please specify) _____
22. Has a **health professional** (i.e. doctor, nurse, dietician) ever taught you any of the following strategies to prevent an accidental exposure to a food allergen?
- ☐ How to read food package labels to identify the allergenic food
 - ☐ How cross-contamination occurs from allergenic foods to "safe" ones
 - ☐ How to ask questions about food preparation in restaurants
 - ☐ How to prepare school personnel to manage food allergies
 - ☐ Other (please specify) _____

23. Have you ever reviewed with your child the **ways to avoid accidental exposure** to food allergens by (check all that apply):

☐ Reading labels of packaged foods
☐ Inquiring about food preparation methods in cafeterias/restaurants
☐ Inquiring about cross-contamination of foods with allergenic foods
☐ Avoid sharing foods from friends
☐ I have not taught my child specific ways to avoid food allergens
☐ Other (please specify) _____

Sometimes, despite efforts to avoid the accidental ingestion of an allergenic food, accidents happen. The next group of questions refer to past allergic reactions that your child may have experienced since the initial diagnosis of a food allergy. (This does not refer to the initial allergic reaction that led to the diagnosis.)

24. Has your child ever experienced an **allergic reaction** since being diagnosed?

☐ Yes (Go to question # 24)
☐ No (Go to question # 28)

25. Approximately **how many** allergic reactions to foods has your child experienced since the diagnosis of food allergy was established?

☐ None
☐ One
☐ Two
☐ Three or more
☐ Multiple/too numerous to count

26. **Where** did the reaction(s) begin? (Insert # of reactions at each location)

☐ Classroom
☐ School cafeteria
☐ School recess
☐ Field trip
☐ School bus
☐ Restaurant
☐ Friend's home
☐ Family home
☐ On vacation
☐ Other (please specify) _____

27. What did the person who responded to the allergic reaction do to **treat the reaction?** (check all)

☐ Administered epinephrine (EpiPen®) immediately
☐ Administered antihistamine (Benadryl®)
☐ Administered asthma medications (Ventolin®, Bricanyl®)
☐ Called an ambulance
☐ Transported child to hospital via car
☐ Took child to family doctor
☐ Wait and see – until symptoms passed
☐ Other (please specify) _____

28. How many of these reactions occurred at **school?**

☐ None
☐ One
☐ Two
☐ Three or more

The following questions pertain specifically to the management of your child's food allergies in school.

29. How did you **approach the issue** of your child's food allergy with the school personnel? (check all)

☐ Talked to the school principal
☐ Talked to the child's teacher (homeroom and subject)
☐ Talked to the school nurse
☐ Talked to other parents
☐ I had the doctor call the school principal
☐ I distributed written material
☐ I arranged for a video to be shown
☐ I made a formal presentation
☐ I arranged for staff training in EpiPen® administration
☐ I didn't tell anyone at school
☐ Other (please specify) _____

30. Who provided the school with an **action plan / poster** for the treatment of allergic reactions?

☐ You filled out a poster/plan provided by the school
☐ You made up your own poster/plan
☐ Your child's allergist/pediatrician
☐ Your child's family doctor
☐ The school nurse
☐ There is no such action plan/poster
☐ Other (please specify) _____

31. Do you **provide medications** (such as EpiPens®) to be used at school in the case of an allergic reaction in your child? (Insert # of EpiPens®)

☐ Yes (Go to question # 32)
☐ No (Go to question # 31)

32. What are some of the reason(s) **why you do not provide medications** (such as EpiPens®) to be used at school? (check all)

☐ The cost of the medication
☐ I don't feel it is necessary
☐ My child knows the foods to avoid
☐ My child has never had a life-threatening (anaphylactic) reaction
☐ My child has never reacted to air-borne allergens
☐ The medication is not easily available in my area
☐ Other (please specify) _____

33. Next, I will read to you a list of **topics pertaining to food allergies** and I will ask you **who**, to the best of your knowledge, has taught this topic to school personnel in the past? Possible people who have taught school staff:

1 = you or a member of your family
 2 = school nurse
 3 = doctor
 4 = principal
 5 = other
 6 = not taught to your knowledge
 7 = don't know

Topics pertaining to food allergies:

☐ Signs and symptoms of an allergic reaction/anaphylaxis
☐ Triggers of an allergic reaction
☐ Strategies to prevent an allergic reaction from occurring
☐ Protocol for responding to an allergic reaction
☐ How and when to administer epinephrine (e.g. EpiPen®)
☐ Description of what previous allergic reactions have been like

34. Do you provide **food for your child to eat at school?**

☐ All of the meals/snacks
☐ Some foods (Child buys food at school/eats out occasionally)
☐ No never – child buys all food
☐ Other (please specify) _____

35. **Where** does your child eat his/her meals at school?

☐ In the school cafeteria at a regular table
☐ In the school cafeteria at a food-restricted table
☐ In the nurse's office/health room
☐ In the classroom
☐ Other (please specify) _____

36. Does the school attempt to **minimize the risk of accidental exposure** to foods known to cause allergic reactions by asking parents and students to avoid sending these foods to school for recess and lunch?
- ☐ Yes, *all* parents and students are asked not to bring allergenic foods to school
- ☐ Yes, *only* students in the same classroom are asked not to bring in such foods
- ☐ No, the school does not attempt to restrict foods brought into the school
- ☐ I don't know
- ☐ Other (please specify) _____
37. Does the school apply the **same rules about reducing the risk** of accidental exposure to food allergens when carrying out other activities, such as field trips, celebrations, science/heritage fairs, crafts, fund-raisers?
- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ No
- ☐ Don't know
- ☐ Other (please specify) _____
38. Does the **school notify you** about the planned activities involving food that may be associated with increased risk, such as birthday parties, trips, celebrations, etc.?
- ☐ Yes, always
- ☐ Yes, most of the time
- ☐ Only through general school notes and newsletters
- ☐ No
- ☐ Other (please specify) _____
39. Does the school periodically send home **reminder letters/newsletters** to all students in the school informing them about the presence of food allergic students in the school?
- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Other (please specify) _____
40. Does your child travel to and from school on the **school bus**?
- ☐ Yes (Go to question # 38)
- ☐ No (Go to question # 40)
41. To the best of your knowledge, how much does the **bus driver know** about your child's food allergy? (check all)
- ☐ He/she has been taught about signs and symptoms of anaphylaxis
- ☐ He/she has been taught how to administer an EpiPen®
- ☐ He/she knows that my child has a food allergy
- ☐ He/she is not aware of my child's food allergy
- ☐ I don't know
- ☐ Other (please specify) _____

42. Has your child ever experienced an allergic reaction while travelling on the school bus?

- ☐ Yes
☐ No

43. How well does your **school accommodate** your child's food allergy?

- ☐ Excellent
☐ Very good
☐ Satisfactory
☐ Inadequate
☐ Other

44. How would you rate the **receptiveness** of other parents and students to requests from the school not to bring certain foods into the school?

- ☐ Excellent, no resistance
☐ Very good, minor resistance
☐ Poor, a lot of resistance
☐ Other – They don't understand and they send in the foods anyway
☐ Don't know

45. In general, on a scale from 1 to 10, **how safe** do you feel your child is while attending school with a life-threatening food allergy?

Not at all safe 1 _____ 10 As safe as if I were
 taking care of him/her

Would you like to elaborate on your reasons for choosing that number?

46. Are you a member of a **Support Group** for people living with food allergies?

- ☐ Yes (please specify) _____
☐ No
☐ No, but I would like to find a support group to join
☐ Other (please specify) _____

Thank-you for your time. During the focus group discussions, you (or your teen) will be given further opportunities to discuss issues related to living with a life-threatening food allergy.

APPENDIX E

Questions for Focus Groups

Opening Remarks

Thank you for agreeing to participate in this study of families of children and teens with life-threatening food allergies. You have been asked to participate in this study because you (in the case of a teen)/your child (in the case of a parent) have/has a food allergy.

Your participation in this discussion is completely voluntary, and you may decide to stop participating at any time if you so wish. The discussion will be audio-taped so that I may transcribe the discussion more easily. However, you do not have to state your name through the discussion, and all identifying information will be removed from the written transcription. I will be the only person permitted to listen to the tape, and I will erase the tape at the completion of the study. Throughout the study, I will store the tape in a locked cabinet, and I will be the only person with access to the key. The results of the study will be summarized into general ideas and themes that we have discussed here today. If you have any questions about the research process, please feel free to ask me, either now or later.

The Questioning Route

1. To begin, I would like to go around the table and have everybody introduce themselves and briefly tell us about your child with the food allergy, i.e. Whether you have a son or a daughter, how old he/she is, and the foods that he/she is allergic to. Then we will be familiar with each other and know where we are all coming from in this discussion.
2. I would like to ask you to think back to the time when your child/children was first diagnosed with a severe food allergy. What was that experience like for you, i.e. How did you feel at the time and, when you left the doctor's office or clinic after receiving the diagnosis, did you feel adequately prepared to manage your child's food allergy?
3. Now I would like you to think ahead from the time of the initial diagnosis. Do you feel now that you understand what needs to be done to safely manage your child's food allergy? Do you feel in control of the allergy now?
4. How do you think your lives and your child's life has been changed by having to live with a life-threatening food allergy? How is your child's life different than if he/she didn't have a food allergy, and, if you have other children, how is this child's life different from the lives of their siblings who do not have a food allergy?
5. How safe do you think your child is while attending school with a severe food allergy?
6. I know that the reality of living with a food allergy involves weighing the risks in all situations. While I do not mean to imply that any of you are negligent in managing your child's food allergy, are their times or situations when you take risks – calculated risk – with foods that could possibly cause a reaction? If so, how do you weigh out the risk when making these decisions?
7. When you think about all of the issues you have to face living with a child who has a life-threatening food allergy, what stands out as the most difficult issue or situation? What is the worst part about living with a food allergy?

8. Can you think about anything positive or beneficial that comes with living with a food allergy?
9. If you think back over all of the things we have discussed in this focus group, are there any other obstacles or barriers that need to be overcome in order to improve the lives of children and teens living with life-threatening food allergies?

APPENDIX F



Memorial

University of Newfoundland

Human Investigation Committee
Research and Graduate Studies
Faculty of Medicine
The Health Sciences Centre

March 4, 2003

Reference #03.13

Ms. Janice D. Butler
C/o Dr. Sharon K. Buehler
Community Health
Faculty of Medicine
Health Sciences Centre

Dear Ms. Butler:


This will acknowledge the correspondence dated February 27, 2003, wherein you clarify issues, provide a copy of a revised consent form, questionnaires and letters for your research study entitled **"Living with life-threatening food allergies: The needs and behaviors of children and teens attending school in Newfoundland"**.

The Chairs' of the Human Investigation Committee reviewed your correspondence and approved the revised consent form, questionnaires, letters and the clarified issues, as submitted and granted **full approval** of your research study. This will be formally reported to the full Human Investigation Committee at the meeting scheduled for **March 6, 2003**.

Please be advised that the Human Investigation Committee currently operates according to the Good Clinical Practice Guidelines, the Tri-Council Policy Statement and applicable laws and regulations.

Sincerely,

Sharon K. Buehler, PhD
Co-Chair
Human Investigation Committee



Richard S. Neuman, PhD
Co-Chair
Human Investigation Committee

SKB;RSN\jd

C Dr. C. Loomis, Vice-President (Research)
Dr. R. Williams, Vice-President, Medical Affairs, HCC

APPENDIX G

**Janice Butler MN, Graduate Student
Memorial University of Newfoundland**

[date]

Name of Assistant Director, Programs

Name and address of School Board

Dear Mr./Ms. _____

**RE: Living with Life-threatening Food Allergies:
The Needs and Behaviors of Children and Teens Attending School in Newfoundland**

I am a graduate student in the Master of Science (Medicine) program in the Division of Community Health at Memorial University. As a partial requirement for the degree, I am required to conduct a study. This study is under the direction and guidance of Dr. Sharon Buehler, and has received full approval from the Human Investigation Committee.

The **purpose** of the study is to describe the needs and behaviors of children and teens with life-threatening food allergies, and to describe the approach taken by schools to manage students with these allergies. The results of this study may provide insight into unidentified needs of children, and may provide valuable guidance for schools that are faced with the ever-increasing numbers of students with food allergies.

I would like to approach the **Principals of a random sample of schools in the province** and ask them to consider participating in the study. In order to be eligible for this study, the school must have at least one student with a life-threatening food allergy (who carries epinephrine (e.g. an EpiPen®)) in attendance during the academic year. Only schools with a minimum enrolment of 100 students in Districts 1 to 10 will be considered for this study. Principals of schools in the province will be randomly approached until a total **30 schools in the province** have participated in the study. The Principal may also suggest that another staff member who is responsible for managing food allergies in the school be interviewed for the study.

If a Principal (or designate) agrees to participate in the study, then we will agree upon a convenient time for me to conduct a **telephone interview that will last 15 to 20 minutes**. The focus of the interview will be on the current management of students with life-threatening food allergies. For schools in Districts 8, 9 and 10, I will also be asking the Principal for his/her assistance by distributing a letter from me to the parents of students in the school with food allergies. These parents will subsequently be invited by me to participate in a focus group discussion of the needs and behaviors of their children who are living with life-threatening food allergies.

Participation in the study is completely voluntary. Data collected during the study will be kept confidential, and no individual, family, principal or school will be identifiable in the final report. At the completion of the study, all Principals will be offered a summary of the research report.

I am writing at this time to ask for your support and permission to approach *individually* the Principals of the schools in your district. I would like to offer each randomly selected Principal the opportunity to decide whether or not to participate in this study. I hope that schools will welcome this type of research as a method of providing meaningful direction to future policies on the safe management of a growing number of students with food allergies attending schools in this province.

If you would like clarification about the details of the study, or wish to receive a complete copy of the proposal, I will gladly send it to you. You may contact me at 726-2367 or by e-mail: jdbutler@roadrunner.nf.net.

Thank-you for your support and consideration.

Sincerely yours,

Janice Butler MN

APPENDIX H

Janice Butler MN, Graduate Student
Memorial University of Newfoundland
Division of Community Health, Faculty of Medicine
The Health Sciences Centre
St. John's, NF

[date]

Name of principal
Address of school

Dear Mr./Ms _____

**RE: Living with Life-threatening Food Allergies:
The Needs and Behaviors of Children and Teens Attending School in Newfoundland**

I am a graduate student in the Master of Science (Medicine) program in the Division of Community Health at Memorial University. As a partial requirement for the degree, I am required to conduct a study. This study is under the direction and guidance of Dr. Sharon Buehler. This letter is to explain the purpose of the study, and to seek your participation.

The purpose of the study is to describe the needs and behaviors of children and teens with life-threatening food allergies, and to describe the approach taken by schools to manage students with these allergies. The results of this study may provide insight into unidentified needs of children, and may provide valuable guidance for schools that are faced with the ever-increasing numbers of students with food allergies.

Your school was randomly selected from a list of all schools in the province, provided by the Newfoundland and Labrador School Boards Association. In order to be eligible for participation in this study, there must be at least one student with a food allergy (severe enough to carry epinephrine (i.e. EpiPen®)) enrolled in your school for the 2002-2003 academic year. If your school is eligible to participate, and you consent, I would like to conduct a short telephone interview (**approximately 15-20 minutes**) with you, or another consenting staff member who is responsible for managing students with food allergies.

During collection and analysis of the data, all material for the study will be kept confidential in a secure locked area accessible only to me. The telephone interview will not be taped, and individuals and schools will not be identifiable in the final report. I will also provide you with a summary of the research report upon completion of the study.

I will telephone you at your school in the next week or two to answer any questions you may have about the study, and to determine whether you have at least one student with a food allergy. Your participation is completely voluntary. If you are willing to take part, we can agree upon a convenient time to conduct the telephone interview.

Thank you for your support. Janice Butler (726-2367 or jdbutler@roadrunner.nf.net)

APPENDIX I

**Janice Butler MN, Graduate Student
Memorial University of Newfoundland**

May 1, 2003

Name of principal (School District 8, 9, and 10)

Address of school

Dear Mr./Ms _____

**RE: Living with Life-threatening Food Allergies:
The Needs and Behaviors of Children and Teens Attending School in Newfoundland**

I am a graduate student in the Master of Science (Medicine) program in the Division of Community Health at Memorial University. As a partial requirement for the degree, I am required to conduct a study. This study is under the direction and guidance of Dr. Sharon Buehler. The study has received full ethical approval from Memorial University, and I have received permission to contact you from the Assistant Director (Programs) in your school district. This letter is to explain the purpose of the study, and to seek your participation.

The purpose of the study is to describe the needs and behaviors of children and teens with life-threatening food allergies, and to describe the approach taken by schools to manage students with these allergies. The results of this study may provide insight into unidentified needs of children, and may provide valuable guidance for schools that are faced with the ever-increasing numbers of students with food allergies.

Your school was randomly selected from a list of all schools in the province, provided by the provincial Department of Education. In order to be eligible for participation in this study, there must be at least one student with a food allergy (severe enough to require epinephrine (i.e. EpiPen®)) enrolled in your school for the 2002-2003 academic year. If your school is eligible to participate, and you consent, I would like to conduct a short telephone interview (**approximately 15-20 minutes**) with you, or another consenting staff member who is responsible for managing students with food allergies.

During collection and analysis of the data, all material for the study will be kept confidential in a secure locked area accessible only to me. The telephone interview will not be taped, and individuals and schools will not be identifiable in the final report. I will also provide you with a summary of the research report upon completion of the study.

A **second phase** of the study involves **families of children with severe food allergies**. I would like to interview parents of children with allergies and invite them to participate in a focus group discussion. The purpose of this part of the study is to examine the needs and behaviors of children and teens living with life-threatening allergies. I am asking for your assistance in contacting these families. Enclosed is a letter to parents explaining the study. If you agree, I would ask that you give a copy of the letter to the parents of the students in your school with food allergies (severe enough to require an EpiPen®). Participation in the study is completely voluntary. If they are interested in learning more about the study, they can choose to contact me through means described in their letter. I will answer their questions about the study and arrange an interview with the family upon their consent. As was described earlier, confidentiality will be assured. Individuals and families will not be identifiable in the final report. I will also offer the families a summary of the research report upon completion of the study.

I will telephone you at your school in the next week or two to answer any questions you may have about the study, and to determine whether you have at least one student with a food allergy. Your participation is completely voluntary. If you are willing to take part, we can agree upon a convenient time to conduct the telephone interview.

Thank you for your support,

Janice Butler MN (726-2367 or jdbutler@roadrunner.nf.net)

APPENDIX J

**Janice Butler MN, Graduate Student
Memorial University of Newfoundland**

May 1, 2003

Dear Parent

**RE: Living with Life-threatening Food Allergies:
The Needs and Behaviors of Children and Teens Attending School in Newfoundland**

I am a graduate student in the Master of Science (Medicine) program in the Division of Community Health at Memorial University. As a partial requirement for the degree, I am required to conduct a study. This study is under the direction and guidance of Dr. Sharon Buehler and has received full ethical approval from Memorial University. This letter is to explain the purpose of the study, and to seek your participation.

The **purpose** of the study is to describe the needs and behaviors of children and teens with severe food allergies, and to describe the approach taken by schools to manage students with these allergies. The results of this study may provide insight into unidentified needs of children, and may provide valuable guidance for schools that are faced with the ever-increasing numbers of students with food allergies.

The Principal of the school that your child attends has given you this letter on my behalf because your child has a food allergy that is severe enough to require epinephrine (e.g., an EpiPen®). I would like to invite you to participate in this study. If you agree to consider participating, then you may contact me and I will gladly answer any questions you may have before you make the final decision to participate.

This study will be conducted in **two parts**. First, I will interview you over the telephone for **approximately 20 - 25 minutes** (at no cost to you). During this interview, I will ask you general questions about the history of your child's food allergy and your approach to managing the allergy. In the second part of the study, I will invite you to participate in a focus group discussion with other parents. A focus group is a very relaxed discussion amongst a small group of parents of children with food allergies where you are free to discuss what it is like living with a child with a severe food allergy. If your child is a teenager, I may also invite him/her to participate in a separate discussion with other teens with food allergies. The focus group discussion will be held in your local area, and will last approximately one to one and a half hours.

Throughout the study, all information gathered will be kept confidential in a secure locked area accessible only to me. Individuals and families will not be identified in the final report. At the end of the study, I will offer you a summary of the research report, as well as educational information and contact lists for community resources that assist families to live with food allergies. Your decision to participate in this study (and the decision of your teenaged child) is completely voluntary, and you may choose to withdraw from the study at any time for any reason.

If you would like to learn more about this study, please contact me through one of the following:

1. Home telephone: 709-726-2367
2. E-mail: jdbutler@roadrunner.nf.net
3. Send me your name and phone number, and a convenient time to contact you, using the enclosed stamped, self-addressed envelope. I will contact you.

Thank you for your support and cooperation on this research project,

Janice Butler MN (726-2367 or jdbutler@roadrunner.nf.net)

APPENDIX K

**Living with Life Threatening Food Allergies:
The Needs and Behaviours of Children and Teens Attending School in
Newfoundland**

Telephone Script for Informed Consent: Principal

1. Hello, my name is Janice Butler. I am a graduate student in Community Health at Memorial University. I would like to speak with (name of Principal).
2. Hello, my name is Janice Butler. Am I speaking with (name of Principal)?
If yes, go to #3. If no, ask about a convenient time to call back.
3. I am a graduate student in Community Health at Memorial University. I recently wrote you a letter regarding a study I am conducting as a partial requirement of a Master's Degree. I am researching the needs and behaviors of children and teens with life-threatening food allergies attending school in Newfoundland. *Allow time for recall of the letter, and assist if necessary.*
4. For this study, I will be interviewing a random sample of Principals in the province. Your school was randomly selected from a list of all schools in Districts 1 to 10 of the province, provided by the Newfoundland and Labrador School Boards Association. In order to be eligible for participation in this study, there must be at least one student with a food allergy (severe enough to carry epinephrine (i.e. Epipen®) enroled in your school this year. Do you have at least one student with such a severe food allergy in your school? *If yes, go to # 5. If no, go to CLOSURE.*
5. In some schools, the Principal has designated another staff member as the person who is primarily responsible for managing food allergies in the school. Is this the case in your school? *If no, then proceed to # 6. If yes, then ask the Principal for permission to approach that other staff member to participate in a short telephone interview (approximately 15-20 minutes). In this case, all parts of this telephone script will be reviewed with the designated staff person.*
6. If you agree to consider participating in this study, then we can set a time which is convenient for you so that I can call back and conduct a telephone interview which will last approximately 15-20 minutes. If you do not already have this information at your fingertips, I will need to know the total number of students in your school, the number of students with severe food allergies, and the foods to which they are allergic. (N.B. For Principals in Districts 8, 9, and 10, I will also be asking for your assistance by giving a letter from me to the parents of the students with life-threatening food allergies in your school. This letter will invite these parents to participate in the study.) *If it is convenient to proceed right now, then go to # 7. If not, then agree upon a time to call back, verify that I have the correct person, and begin at #7. If the Principal refuses to participate, go to CLOSURE.*

7. Before proceeding any further, I would like to read the following consent statement to you to make sure that you understand the study:

If you agree to participate in this study, you will be interviewed over the telephone for 15-20 minutes (*for Districts 8, 9, and 10: and asked to give a letter from me to parents of students with severe food allergies at your school*). There are no known risks from participating in this study, and it is not known whether this study will benefit you personally. The information you give to me will remain confidential, and no individual person or school will be identified in the results. Your participation in the study is completely voluntary, and you may refuse to answer any questions at any time. Do you have any questions?

Are you ready and willing to begin the interview?

CLOSURE

Thank-you very much for your time. If you have any further questions about the study, you may contact me at the numbers provided in your letter.

APPENDIX L

**Living with Life Threatening Food Allergies:
The Needs and Behaviours of Children and Teens Attending School in
Newfoundland**

Telephone Script for Informed Consent : Parent

1. Hello, my name is Janice Butler. I am a graduate student in Community Health at Memorial University. I would like to speak with (name of Parent).
2. Hello, my name is Janice Butler. Am I speaking with (name of Parent)?
If yes, go to # 3. If no, ask about a convenient time to call back.
3. I am a graduate student in Community Health at Memorial University. You recently received a letter from the Principal of the school your child attends regarding a study I am doing as part of a Master's Degree. I am researching the needs and behaviours of children and teens with life-threatening food allergies attending school in Newfoundland. The Principal gave you this letter because you have a child with a food allergy. *Allow time for recall of the letter, and assist if necessary.*
4. Do you have a child who attends school (name of school) and who has a food allergy for which he/she is prescribed epinephrine (i.e. EpiPen®)? *If no, go to CLOSURE. If yes, go to # 5.*
5. For this study, I will be interviewing parents of children with life-threatening food allergies to get some background information about your child's allergy and ways in which you manage the allergy in school. This telephone interview will be held (at no cost to you) at a time that is convenient for you, and the interview will last approximately 20-25 minutes.

I will also be inviting parents to attend a focus group discussion where parents are free to discuss what it is like living with a child with a severe food allergy. (If the child is a teenager, then he/she may also be invited to attend a focus group discussion with other teens). The focus group discussion will be held in your local area and will last one to one and a half hours.

Do you have any questions at this time? *Answer questions*

6. If you agree to consider participating in this study, then we can set a time that is convenient for you so that I can call back and conduct a telephone interview which will last 20-25 minutes. *If it is convenient to proceed right now, then go to # 7. If not, then agree upon a time to call back, verify that I have the correct person, and begin at # 7. If the parent refuses to participate, go to CLOSURE.*
7. Before I begin the interview, I would like to read the following consent statement to make sure that you understand the study:

If you agree to participate in this study, you will be interviewed over the telephone for 20-25 minutes. You will also be asked to attend a focus group discussion on living with food allergies to be held later. There are no known risks from participating in this study, and it is not known whether this study will benefit you personally. The information you give to me will remain confidential, and no individual person, family or school will be identified in the results. Your participation in the study is completely voluntary, and you may refuse to answer any questions at any time. Do you have any questions?

Are you ready and willing to begin the interview?

CLOSURE

Thank-you very much for your time. If you have any further questions about the study, you may contact me at the numbers provided in your letter.

APPENDIX M

Consent to Take Part in Health Research

TITLE: Living with Life Threatening Food Allergies:
The Needs and Behaviors of Children and Teens Attending School in Newfoundland

INVESTIGATOR: Janice D. Butler
Telephone 726-2367

You have been asked to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researcher will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

If you decide not to take part or to leave the study this will not affect you in any way.

Introduction/Background:

The results of this study may provide insight into the needs of children and teens with life-threatening food allergies attending school in Newfoundland. The study may also provide guidance to schools that are faced with the ever-increasing numbers of students with food allergies.

Purpose of study:

The purpose of this study is to describe the needs and behaviors of children and teens with life-threatening food allergies.

Description of the study procedures:

If you agree to participate, you will be asked to join a focus group discussion with other parents of children with food allergies. The purpose of the focus group will be to discuss what it is like living with a child who has a severe food allergy. The focus group will be held in your local area and will last one to one and a half hours.

There are no known risks from participating in this study. It is not known whether this study will benefit you personally.

Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

Initials: _____

Signature Page

Study title: Living with Life Threatening Food Allergies:

The Needs and Behaviors of Children and Teens Attending School in Newfoundland

Name of principal investigator: Janice D. Butler (726-2367)

To be filled out and signed by the participant:

Please check as appropriate

I have read the consent [and information sheet].

Yes { }

No { }

I have had the opportunity to ask questions/to discuss this study.

Yes { }

No { }

I have received satisfactory answers to all of my questions.

Yes { }

No { }

I have received enough information about the study.

Yes { }

No { }

I understand that I am free to withdraw from the study

Yes { }

No { }

- at any time
- without having to give a reason
- without affecting me in any way

I understand that it is my choice to be in the study and that I may not benefit. Yes { }

No { }

I agree to take part in this study.

Yes { } No { }

Signature of participant

Date

Signature of witness

Date

To be signed by the investigator:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of investigator

Date

Telephone number: _____

Initials: _____

APPENDIX N

Faculty of Medicine, Memorial University of Newfoundland

Consent to Take Part in Health Research

TITLE: Living with Life Threatening Food Allergies:
The Needs and Behaviors of Children and Teens Attending School in Newfoundland

INVESTIGATOR: Janice D. Butler
Telephone 726-2367

You have been asked to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researcher will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

If you decide not to take part or to leave the study this will not affect you in any way.

Introduction/Background:

The results of this study may provide insight into the needs of children and teens with life-threatening food allergies attending school in Newfoundland. The study may also provide guidance to schools that are faced with the ever-increasing numbers of students with food allergies.

Purpose of study:

The purpose of this study is to describe the needs and behaviors of children and teens with life-threatening food allergies.

Description of the study procedures:

If you agree to allow your child to participate, your child will be asked to join a focus group discussion with other children who have food allergies. The purpose of the focus group will be to discuss what it is like living with a severe food allergy. The focus group will be held in your local area and will last one to one and a half hours.

There are no known risks from participating in this study. It is not known whether this study will benefit you or your child personally.

Liability statement:

Signing this form gives us your consent to allow your child to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

Initials: _____

Signature Page

Study title: Living with Life Threatening Food Allergies:

The Needs and Behaviors of Children and Teens Attending School in Newfoundland

Name of principal investigator: Janice D. Butler (726-2367)

To be filled out and signed by the participant:

Please check as appropriate

I have read the consent [and information sheet].	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study.	Yes { }	No { }
I have received satisfactory answers to all of my questions.	Yes { }	No { }
I have received enough information about the study.	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }

- at any time
- without having to give a reason
- without affecting me in any way

I understand that it is my choice to be in the study and that I may not benefit. Yes { } No { }

I agree to take part in this study. Yes { } No { }

Signature of participant

Date

Signature of witness

Date

To be signed by the investigator:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of investigator

Date

Telephone number: _____

Assent of minor participant (if appropriate):

Signature of minor participant

Date

Relationship to participant named above

Age

Initials: _____

APPENDIX O

ANAPHYLAXIS ALERT

Life Threatening Allergies

Student: _____ Grade/Teacher: _____

LIFE THREATENING ALLERGIES TO:

Exposure to minute amounts of this allergen can be danergerous to the child. At all times this child must AVOID:

A CHILD WITH A LIFE THREATENING ALLERGY MUST HAVE AN **EPIPEN** (Adrenaline) ACCESSIBLE AT ALL TIMES

Eating Rules/Activity Rules:

POSSIBLE SYMPTOMS OF ANAPHYLAXIS:

- | | | | |
|--|--|---|---|
| <input type="checkbox"/> Tingling in mouth | <input type="checkbox"/> Feeling of fear/anxiety | <input type="checkbox"/> Hives/Itching | <input type="checkbox"/> Wheezing |
| <input type="checkbox"/> Swelling-eyes lip, face, tongue | <input type="checkbox"/> Tightness in throat/chest | <input type="checkbox"/> Flushed face/body | <input type="checkbox"/> Dizziness/unsteadiness |
| <input type="checkbox"/> Vomiting/stomach upset | <input type="checkbox"/> Coughing/Choking | <input type="checkbox"/> Difficulty breathing/ swallowing | <input type="checkbox"/> Loss of consciousness |
| | | | <input type="checkbox"/> Other _____ |

ACTION PLAN:

1. Give EPIPEN immediately at first sign of symptoms. (Give into outer thigh and hold in place for 10 seconds)
EPIPEN is located _____
2. Have child spit out food and rinse mouth. Wash contact area.
3. Give additional medication, if any: _____
4. Transport child immediately to medical facility by ____ car or ____ ambulance (tell dispatcher child is having an anaphylactic reaction)
5. Have someone telephone the medical facility to inform them of the incoming child.
6. Administer an additional EPIPEN (if available) during transport every 15-20 minutes, if breathing difficulties are present.
7. Suggest the child be monitored in medical facility for at least 8 hours, even if symptoms subside. Symptoms may reoccur.

Date: _____ Physician's Signature: _____

Contacts

Parent/Guardian: _____

Tel: _____

Parent/Guardian: _____

Tel: _____

Hospital: _____

Tel: _____

Doctor: _____

Tel: _____

Photo of
Child

